“Hobson’s choice, a horned dilemma or something in between”: a grounded theory explaining women’s experience with adjuvant endocrine therapy in breast cancer survivorship

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Declaration

I, Othman AlOmeir, confirm that this is my own work and that the use of all material from other sources has been properly and fully acknowledged.

Othman AlOmeir

Acknowledgement

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Dedication

I dedicate this thesis

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List of abbreviations

AC	Doxorubicin and Cyclophosphamide
AET	Adjuvant Endocrine Therapy
AHT	Adjuvant Hormone Therapy
AI	Aromatase Inhibitors
AJCC	American Joint Committee on Cancer
BCS	Breast-Conserving Surgery
BCW	Behavioural Change Wheel
BRCA	Breast Cancer gene
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CMF	Cyclophosphamide, Methotrexate and 5 Fluorouracil
COM-B	Capability, Opportunity and Motivation model of Behaviour
CVI	Content Validity Index
DES	Diethylstilboestrol
ENTREQ	Enhancing Transparency in Reporting The Synthesis of Qualitative Research
ER	Oestrogen Receptors
ET	Endocrine Therapy
FDA	Food and Drug Administration
FTT	Fuzzy-Trace Theory
GP	General Practitioner
GT	Grounded Theory
HBM	Health Belief Model
HCP	Healthcare Professional
HER2	Human Epidermal Growth Factor Receptor 2
HR	Hormone Receptor
HT	Hormone Therapy
I-CVI	Item Content Validity Index
IM	Integrative Model
IPA	Interpretive Phenomenological Analysis
MeSH	Medical Subject Heading
NFC	Near Field Communication

NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OTC	Over-The-Counter
PR	Progesterone Receptors
S-CVI	Scale-level Content Validity Index
SCT	Social Cognitive Theory
SDT	Self-Determination Theory
SERM	Selective Oestrogen Receptor Modulators
SRT	Self-Regulation Theory
TDF	Theoretical Domain Framework
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
TST	Temporal Self-regulation Theory
TTM	Transtheoretical Model
UREC	University of Reading Ethics Committee
WHO	World Health Organization

List of publications

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Oral presentation at the Postgraduate Research Showcase, School of Pharmacy, University of Reading on 16th March 2018, titled "A meta-synthesis of the qualitative literature examining adherence to oral anticancer medication using grounded theory".

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Abstract

Introduction: Breast cancer is the most common type of cancer in women across the world. Women are prescribed adjuvant endocrine therapy in hormone receptor (HR) positive cases, which account for two thirds of all breast cancer diagnoses. However, research consistently shows a reluctance by some women to fully adhere to their course of treatment. No study provides a comprehensive theory to explain the challenges of long-term medication taking and the resilience needed to continue within what can be termed breast cancer survivorship.

Aim: To develop a theoretical understanding of women's experiences with hormone therapy following breast cancer diagnosis and initial treatment, using grounded theory.

Methods: A meta-synthesis examined the existing qualitative studies that have assessed women's experiences with taking adjuvant endocrine medication in breast cancer survivorship to develop an in-depth explanatory model using grounded-theory synthesis. These models were validated and further developed by conducting in-depth interviews with breast cancer survivors prescribed adjuvant endocrine therapy, again using grounded theory analysis. The models were converted into sets of pictograms to improve accessibility for educational purposes. The pictograms were content-validated with breast cancer survivors and a panel of healthcare professionals/researchers. Finally, the COM-B model and the behavioural change wheel were explored for the development of potential adherence interventions based on the grounded theory findings.

Results: The work from the systematic review and interview data largely corroborated each other confirming the validity of the findings. Three main categories were identified describing the 1) initial consideration of adjuvant endocrine therapy; 2) adhering to prescribed treatment; and 3) stopping adjuvant endocrine therapy. A core category explained the findings as 'Hobson's choice' or 'a horned dilemma'. The resulted grounded theory models were developed into 93 pictograms to represent the different categories and provide the basis of intervention design and development. A number of interventions were developed to support future adherence in breast cancer survivorship.

Conclusion: It was possible to uncover a world of collectively shared experiences and understandings in the area of breast cancer survivorship. The educational tool designed in this thesis could inform breast cancer survivors and healthcare professionals about these challenges and could potentially improve women's experiences of treatment thus potentially improving their adherence in the future.

Chapter 1: Introduction

1.1 Introduction

Oral anticancer medication is a term used to describe a treatment taken by mouth in order to treat cancer. Oral anticancer medication includes the traditional cytotoxic medicines (e.g. methotrexate, busulfan) as well as the hormone-related medicines (e.g. tamoxifen, cyproterone). The use of oral anticancer medication has increased significantly in recent years such that they have become the primary form of treatment for many types of cancer (Greer et al., 2016). Taking anticancer medications by mouth (rather than, for example, intravenously) improves the quality of patients' lives greatly as it allows patients control over their treatment (i.e. they can administer the medication themselves) and reduces hospital stays significantly (because patients on oral medications can be discharged home) (Findlay et al., 2008). However, despite how convenient it is for patients to take oral anticancer drugs, their use raises a number of issues, in particular the management of side-effects and more importantly the possibility of patient non-adherence as described below (Given et al., 2011).

In terms of the route of drug delivery in any condition, it is well established that patients prefer oral therapy over intravenous therapy (Mastroianni et al., 2012). This is because it is much more convenient to take a medicine at home orally than to go to a hospital or use a needle as a delivery system. Moreover, the shift toward oral therapy gives patients a sense of control over their treatment (Bassan et al., 2014). However, "Drugs don't work in patients who don't take them" (C. Everett Koop, MD, US Surgeon General, 1985), which is particularly key in patients with cancer as adherence to medication is essential for successful treatment.

Non-adherence to medicines has been an obstacle toward successful therapy since the invention of modern medicine, and is responsible for high rates of mortality, development of multiple co-morbidities and unreasonable healthcare costs (Brown and Bussell, 2011). This phenomenon has been studied widely over the years, however, despite decades of investigation, researchers are noted to have been unable to agree on a definition of non-

adherence or decide on a universal method for assessment of the phenomenon and still tend to exaggerate healthcare practitioners' control over the process (Vrijens et al., 2012).

1.2 Breast Cancer

1.2.1 Definition

Breast cancer occurs when the cells in the breast tissue start growing out of control and form a tumour that could invade surrounding tissues or metastasise to different parts of the body. Breast cancer mostly occurs in women; however, the condition can also occur in men but is not as common (American Cancer Society, 2016).

1.2.2 Types

The most common types of breast cancer are;

- Ductal carcinoma in situ is a non-invasive or pre-invasive breast cancer. In ductal carcinoma, the cancerous cells are located in the ducts and have not invaded nearby tissues. In some cases, they can develop into invasive cancers and there is no way of knowing which cases will and which cases will not invade nearby tissues (Girish et al., 2014).

- Invasive (or infiltrating) ductal carcinoma, is considered the most common type of breast cancer. It starts in the milk duct and then breaks into the fatty tissue of the breast, from where it could metastasise into different parts of the body through the lymph nodes or the blood stream. Invasive ductal carcinoma is responsible for 8 of 10 cases of invasive breast cancer (Girish et al., 2014).

- Invasive (or infiltrating) lobular carcinoma starts in the glands that produce milk and can spread to other parts of the body. Invasive lobular carcinoma is responsible for 1 of 10 cases of invasive breast cancer (Girish et al., 2014).

Moreover, there are some less common types of breast cancer such as; inflammatory breast cancer, Paget's disease of the nipple, phyllodes tumour and angiosarcoma. Other types of invasive breast carcinoma include; adenoid cystic carcinoma, low-grade

adenosquamous carcinoma, medullary carcinoma, colloid carcinoma, papillary carcinoma, tubular carcinoma, metaplastic carcinoma, micropapillary carcinoma and mixed carcinoma (American Cancer Society, 2016).

Breast cancer can also be defined by the presence or absence of biological markers such as oestrogen receptors (ER), progesterone receptors (PR) and human epidermal growth factor receptor 2 (HER2). It can be divided into 4 different molecular subtypes which are:

- Luminal A: This type of breast cancer is hormone-receptor positive (HR+) and HER2-, which means it is either ER+ or PR+. This type of cancer constitutes around 74% of breast cancer cases and shows favourable prognosis (Blows et al., 2010).

- Luminal B: This type of breast cancer is HR+ and HER2+. This type is responsible for around 10% of breast cancer cases. Luminal B breast cancers are more difficult to treat than luminal A breast cancers (Blows et al., 2010).

- HER2-enriched: This type of breast cancer is HR- and HER2+. It is responsible for 4% of breast cancer cases and it is considered more difficult to treat than HR+ breast cancers (Blows et al., 2010).

- Triple negative: This type of breast cancer is HR- and HER-. This type is responsible for 12% of breast cancer cases and is considered the most difficult type to treat (Blows et al., 2010).

1.2.3 Risk factors

According to the American Cancer Society several risk factors have been identified that could potentially increase the risk of breast cancer development. Some of these factors include being a woman (100 times more risk than men), having a family history of breast cancer, race and ethnicity (white women are more likely to develop breast cancer), breast density, radiation therapy to the chest, exposure to diethylstilboestrol (DES), alcohol consumption, lack of physical activity, obesity, early menstruation onset before the age

of 12, going through menopause after the age of 55 and a woman's reproductive history (having children over the age of 30 or not having biological children) (American Cancer Society, 2016).

The incidence of breast cancer is strongly related to age as higher breast cancer rates are observed in older women. In the UK between the years 2012-2014, 48% of breast cancer cases were diagnosed in women aged 65 and over. The incidence rates start increasing from around the age of 30. It then reaches a steady rate between 50-65 years of age. The rate then start increasing again by the age of 65 until it reaches a plateau by the age of 85+ (Cancer Research UK, 2019).

Also, a number of genetic changes have been identified that could lead to breast cancer and those can be divided into inherited gene mutations and acquired gene mutations. Inherited gene mutations are believed to be responsible for 5% to 10% of breast cancer cases and are thought to be passed on from parent to child. The most common are mutations in breast cancer gene 1 (BRCA1) and breast cancer gene 2 (BRCA2). Acquired gene mutations occur during a woman's life and the reasons behind it are still unclear, but factors such as being exposed to radiation and some chemicals could play a role in these types of mutations (American Cancer Society, 2016).

1.2.4 Epidemiology

Breast cancer is the most common type of cancer diagnosed in the UK, accounting for 30.8% of all malignant female cancer registrations in 2016 (King and Broggio, 2018). Breast cancer is also the most common cancer in women across the world, albeit with lower incidence rates in most of the developing regions (age-standardised at below 50 per 100,000), compared to Western Europe (92.6 per 100,000) or North America (84.8 per 100,000) (WHO, 2018a). Yet, despite the higher incidence of breast cancer in developed countries, women in poorer countries are noted to be more likely to die from the disease (Bellanger et al., 2018). This is attributed in the main to the lack of early detection programmes as well as the lack of adequate diagnosis and treatment facilities in developing countries (WHO, 2018b). In contrast, improvements in screening, early diagnosis and treatment in higher-income regions have resulted in a continued fall in death rates from breast cancer such that the 2019 annual breast cancer age-standardised

death rate in the EU is estimated to be 13.36 per 100,000 (Malvezzi et al., 2019). For comparison, this mortality statistic is 15.5 per 100,000 in Central and Eastern Europe, 18.4 in Northern Africa, 21.6 in Polynesia (WHO, 2018a).

It is estimated that around 55,000 new cases of breast cancer are diagnosed yearly in the UK. The incidence of breast cancer in females has increased by 64% when compared to the 1970s, and by 6% just in the last 10 years. The incidence is expected to rise by 2% between the year 2014 and 2035. It is estimated that around 296,000 women are currently living with breast cancer in the UK (Cancer Research UK, 2019). In 2015 breast cancer was responsible for 11,399 deaths accounting for 7% of all cancer deaths and is the third most common cause of cancer death in the UK. Also, despite an expected rise in breast cancer incidence in the next 20 years, it is expected that mortality rates will fall by 26% in the same period because of advancements in medicine. (Cancer Research UK, 2019).

1.2.5 Breast cancer staging

Staging is the process of finding out how widespread the cancer is at the time of diagnosis (Singletary and Connolly, 2006). Finding out the stage of the cancer is important in deciding on the treatment and could determine its success. The 'TNM system' was developed for this purpose by the American Joint Committee on Cancer (AJCC) and is the most commonly used system describing cancer staging. This system is divided into three categories, T, N, and M and a number is given to each category to give more details about the cancer, for example T1N2M0 or T2N0MX (Singletary and Connolly, 2006).

1.2.5.1 T category

Describes the size and extent of the main tumour. The way this element is used is by writing the letter T followed by a number from 0 – 4 or the letter X. For example:

TX: Means that the main tumour cannot be measured.

T0: Means that the main tumour cannot be found.

T1 – T4: The higher the number after the T the larger the tumour or the more it has grown into the nearby tissues. Higher numbers are used to describe bigger tumours or wider spread of the tumour (Singletary and Connolly, 2006).

1.2.5.2 N category

Describes whether or not the cancer has spread to nearby lymph nodes and how many lymph nodes are affected. It is represented by N and a number between 0 – 3 or the letter X. For example:

NX: Means that cancer in the nearby lymph nodes cannot be measured.

N0: Means cancer has not reached nearby lymph nodes.

N1 – N3: The higher the number after the N the more lymph nodes contain the cancer (Singletary and Connolly, 2006).

1.2.5.3 M category

Represents metastasis and describes whether or not the cancer has spread to different organs by the use of the letter M followed by number 0, 1 or the letter X. For example:

MX: Means metastasis cannot be measured.

M0: Means cancer has not spread to other parts of the body.

M1: Means cancer has spread to other parts of the body (Singletary and Connolly, 2006).

The TNM system gives a good level of detail about the cancer. After determining the T, N and M combination, the cancer can then be assigned one of five less detailed stages. These stages are 0, I, II, III or IV, as followed:

Stage 0: Represents carcinoma in situ, which means abnormal cells are present but have not spread to nearby tissues.

Stage I - III: The higher the number, the larger the tumour size is and the more it has spread to nearby tissues.

Stage IV: Means that the cancer has spread to other distant parts of the body.

The survival rates of women diagnosed with breast cancer vary by stage of the cancer. Generally, women diagnosed at an early stage of cancer progression have a better survival rate than women diagnosed at a later stage. The 5-year survival rate for women diagnosed with stage 0 or stage I breast cancer is almost 100%. For women diagnosed with stage II breast cancer the 5-year survival rate decreases to 93%; stage III is 72%, and stage IV breast cancer is 22%. Survival rate numbers cannot predict what will happen to each

woman as every person reacts differently to available therapies for different clinical reasons (American Cancer Society, 2016).

1.2.6 Treatment options

After identifying the stage and characteristic of the cancer, a decision is made between the patient and their physician to choose a treatment plan. Usually, women diagnosed with early stage (I or II) breast cancer undergo surgery combined with other types of treatments to prevent the recurrence of the cancer, such as radiation therapy, chemotherapy, targeted therapy and hormone therapy. Women with metastasised breast cancer are primarily treated with systemic therapies, such as; chemotherapy, targeted therapy and hormone therapy (NICE, 2018; Cancer Research UK, 2019). The available treatments are as briefly described below:

1.2.6.1 Surgery

The primary goal of breast cancer surgery is to remove the cancer cells from the breast. This could be achieved either by breast-conserving surgery (BCS) or mastectomy. BCS is the removal of the cancerous cells and a little bit of the surrounding tissue from the breast. Mastectomy could be total mastectomy (removal of the entire breast), modified radical mastectomy (removal of the entire breast and the under-arm lymph nodes), and radical mastectomy (removal of the entire breast, the under-arm lymph nodes and the underlying chest wall muscle). Patients who undergo a mastectomy or BCS could also undergo breast reconstruction surgery (NICE, 2018; Cancer Research UK, 2019).

1.2.6.2 Radiation therapy

Radiation therapy is the use of high-energy beams to destroy cancer cells and is often used after surgery, especially after BCS. Radiation therapy can be divided into two types: external beam radiation and internal radiation (Brachytherapy). External beam radiation is carried out by a machine that emits high-energy rays at the area affected by the cancer. Depending on the cancer staging, this could include the breast, the under-arm area and the chest wall (NICE, 2018; Cancer Research UK, 2019). External radiation therapy is usually administered over a period of 5-7 weeks; however, studies suggests a 3 weeks'

course could be as effective (Haviland et al., 2013). Brachytherapy is carried out by placing a radioactive substance inside the cavity left after BSC for a short period of time. Brachytherapy is often prescribed as a 5-day course. Some patients are treated with both types of radiation therapy based on the stage of the cancer (NICE, 2018; Cancer research UK, 2019).

1.2.6.3 Chemotherapy

Chemotherapy is the treatment of breast cancer using cytotoxic medications. The aim of chemotherapy is to destroy cancerous cells. Chemotherapeutic drugs work in different ways and target cell growth at different phases, therefore, they are often used in multiple combinations to make the treatment more effective (NICE, 2018; Breast Cancer Care, 2016). Chemotherapy is prescribed as neo-adjuvant (before the surgery) therapy to slow the cancer growth and shrink the tumour to make it easier to remove. Also, chemotherapy could be prescribed as an adjuvant (after the surgery) therapy to try and eliminate all the remaining cancerous cells. Chemotherapy is usually given as a cycle every 2 to 4 weeks over a period of 3 to 6 months. It varies depending on the type and stage of cancer, the patient's general health, possible side-effects and the combination chosen (NHS, 2016). Some examples of chemotherapy drugs used for the treatment of breast cancer include; AC (doxorubicin and cyclophosphamide), capecitabine, cisplatin, carboplatin, docetaxel, eribulin, gemcitabine, CMF (cyclophosphamide, methotrexate and 5 fluorouracil), paclitaxel and vinorelbine (NICE, 2018; Breast Cancer Care, 2016).

1.2.6.4 Targeted therapy

This is a new approach to treatment that targets the cancerous cells and leaves other cells unharmed. Targeted therapy can be divided into two classes; those targeted to HER2+ breast cancer and the those targeted to HR+ breast cancer. As mentioned above, HER2+ breast cancer includes both subtypes luminal B and HER2-enriched, which covers around 14% of breast cancer cases. Multiple drugs have been developed targeting the HER2 protein such as monoclonal antibodies (trastuzumab, pertuzumab and ado-trastuzumab emtanasine) and a kinase inhibitor (lapatinib) (NICE, 2018; Cancer Research UK, 2019). Other targeted therapy medication such as palbociclib and everolimus are used in

combination with hormonal therapy medication to improve their effectiveness in treating HR+ breast cancers (luminal A and luminal B), which are responsible for around 84% of breast cancers (NICE, 2018; Cancer Research UK, 2019).

1.2.6.5 Hormone therapy

Hormonal therapy for breast cancer can be divided into two classes; selective oestrogen receptor modulators (SERM) and aromatase inhibitors (AI). They are mostly used as adjuvant therapy after surgery, radiation or both. Throughout this thesis, the term adjuvant endocrine therapy is used to refer to hormone therapy given in this way to patients, and the terms adjuvant endocrine therapy and hormone therapy are used interchangeably. This class of drugs is mostly used with HR+ cancers, if the cancer is HR-, this class of drugs are of no benefit (Fabian and Kimler, 2005).

The first drug in the SERM class is tamoxifen which was first approved in the UK in 1972 (Smith, 2012) and by the FDA (Food and Drug Administration) in America in 1977. Tamoxifen works by competing with oestrogen at the oestrogen receptor in cancerous cells thus preventing oestrogen from binding; it is also an oestrogen partial antagonist (Fabian and Kimler, 2005). One of the advantages of tamoxifen is that it can work in both post- and pre-menopausal women (Smith and Dowsett, 2003). Tamoxifen is taken orally for a duration of 5-10 years and has been the gold standard for treating breast cancer since its introduction (Jordan, 2014). Taking tamoxifen for at least 5 years has shown a reduction of cancer recurrence by 40-50% in the first 10 years. It also has been shown to reduce mortality rates by about 30% in the first decade after diagnosis. Further studies have shown a additional decrease in recurrence and mortality after taking tamoxifen for 10 years instead of 5 (Davies et al. 2013).

Aromatase inhibitors (AI) were first developed in the 1980s from aminoglutethimide, which was originally an anticonvulsant that showed some anti-oestrogenic activity. Aromatase inhibitors are prescribed for post-menopausal women diagnosed with HR+ breast cancer. In post-menopausal women, oestrogen is no longer produced from the ovaries, however, some of it is still produced in body fat by an enzyme called aromatase. This class of drugs work by binding to the enzyme aromatase and stopping it from working, thus ensuring there is less oestrogen in the body. Aromatase inhibitors are

divided into 1st, 2nd and 3rd generation according to their order of development. They are then classified into type 1 and type 2 according to their mechanism of action. Type 1 aromatase inhibitors are steroidal in nature and work by irreversibly binding to aromatase, thus, inactivating the enzyme. An example of a 3rd generation type 1 aromatase inhibitor is exemestane. Type 2 aromatase inhibitors are non-steroidal in nature and bind reversibly to the aromatase enzyme. Examples of 3rd generation type 2 aromatase inhibitors are anastrozole, letrozole and vorozole (Smith and Dowsett, 2003). The use of aromatase inhibitors for 8 years after diagnoses has been encouraged in order to reduce the risk of cancer recurrence (Goss et al., 2005).

In the UK, the National Institute for Health and Care Excellence (NICE) recommends offering tamoxifen as the initial adjuvant hormonal therapy for pre-menopausal women with invasive breast cancer or offering an aromatase inhibitor to those who are post-menopausal (with tamoxifen permissible in this group in specific circumstances) (NICE, 2018). Since 2018, NICE also recommends offering *extended* therapy (total duration of hormone therapy of more than 5 years) to women who have taken tamoxifen for an initial 5 years by either switching those who are post-menopausal to an aromatase inhibitor or by asking pre- and post-menopausal women to continue taking tamoxifen (NICE, 2018).

1.3 Adherence to medication

1.3.1 Background, history and definitions

One might argue that the first general episode of non-adherence is Eve eating the apple in the garden of Eden! However, the first incident of non-adherence to a therapeutic regimen was documented by Hippocrates in 400BC (Haynes and Sackett, 1979). In modern medicine, Robert Koch in the year 1882 recognised patient non-adherence to tuberculosis treatment (Teller, 1988). In more recent times, the problem of non-adherence was brought to the attention of healthcare providers in the 1950s when a study of outpatient 'compliance' with tuberculosis treatment was first published (Dunbar-Jacob et al., 1991). In the 1970s, the problem of non-adherence was recognized as a poorly studied and understood phenomenon (Dunbar-Jacob et al., 1991). Between 1961 and 1974, only 245 non-adherence articles were published, which reflects how little attention was given to studying non-adherence (Vermeire et al., 2001). Then in 1974, McMaster University

Medical Centre Workshop/Symposium on compliance initiated large-scale research into this phenomenon, with the publication of Haynes and Sackett's first book into this matter titled "Compliance with Therapeutic Regimens" (Haynes and Sackett 1976). This was followed with another more comprehensive book entitled "Compliance in Health Care" in the year 1979 (Haynes and Sackett, 1979).

Historically, a lot of negative terms were used to describe patient non-adherence. Terms such as ignorant, careless, defaulters, recalcitrant, irresponsible and vicious were used between the 1890s and 1940s (Lerner et al., 1998). After that time, terms such as faithless, unreliable and untrustworthy were also used in research papers up until the 1960s (Dixon et al., 1957). This was followed by usage of the term compliance, which was the first term to describe the phenomenon being discussed (Krigsman, 2007). Compliance was introduced as a medical subject heading (MeSH) in 1975 (Blackwell, 1992).

In the year 1993, a shift toward the use of the term adherence instead of compliance was observed (O'Brien et al., 1992). These terms are often used interchangeably and are considered to be synonymous (Vrijens et al., 2012). However, there is a difference in the connotation of the two terms. Compliance is "the extent to which a person's behaviour in terms of taking medications, following diets, or executing lifestyle changes coincides with medical or health advice" (Haynes and Sackett, 1979), while adherence is "the extent to which a person's behaviour (taking medication, following a diet, and/or executing lifestyle changes) corresponds with agreed recommendations from a healthcare provider" (Sabaté and Organization, 2003). A shift toward the use of adherence has been advocated because it reflects the importance of cooperation between the patient and their healthcare provider. Moreover, it shows that patients are not passive and obedient and that it is necessary to understand their perspective. Adherence was introduced as an official MeSH term in the year 2009. Concordance is another term that is used to describe patient compliance with their treatment. The term concordance is used by many as a synonym of compliance or adherence. However, it is a completely different term. While compliance and adherence are used to describe patients' behaviour in regard to taking their treatment, concordance is used to describe the nature of the consultation between patients and health care providers (Vrijens et al., 2012). Concordance is defined as "the consultation process whereby the prescriber and the patient agree on a therapeutic decision that incorporate both views (Donyai, 2019). Other terms such as pharmionics, and persistence are also

used to describe patient deviation from their treatment plan but not very commonly (Vrijens et al., 2012). Figure 1-1 shows a historical timeline relating to the study of adherence.

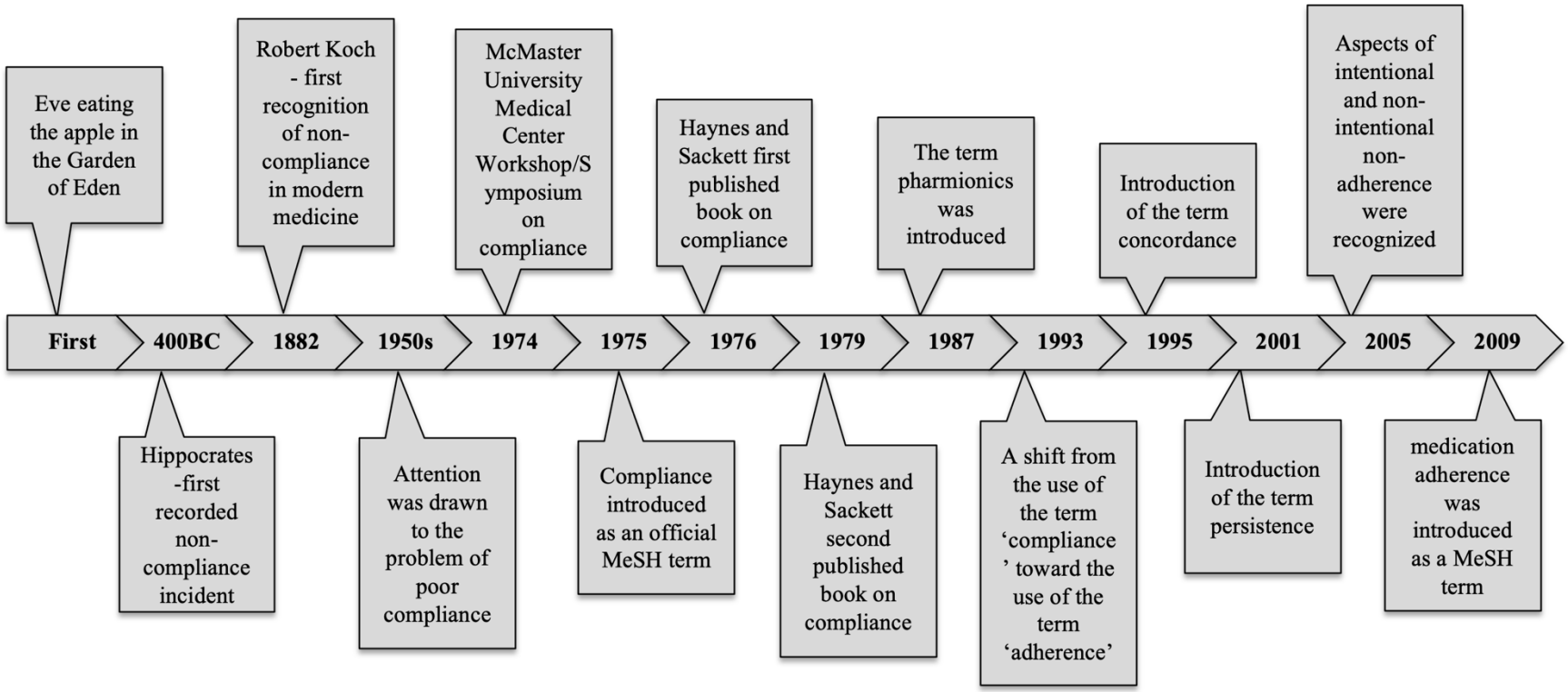


Figure 1-1: The timeline of significant historical events of adherence research and the development of the terms used to describe it.

1.3.2 Types of medication non-adherence

The reasons behind patients' non-adherence are complex and often divided into two categories for ease of reference; intentional and unintentional non-adherence (Wroe, 2002). Unintentional non-adherence is defined as "a passive process in which the patient may be careless or forgetful about properly adhering to the treatment regimen" (Lowry et al., 2005). Many factors play a role in this type of non-adherence such as complexity of the treatment, poor communication between the patient and the healthcare provider, patient inability to take the medicine and the most common factor is forgetfulness. Unintentional non-adherence is a major problem and is considered a predictor of intentional non-adherence if not addressed properly (Gadkari and McHorney, 2012).

Intentional non-adherence has been defined as "an active process in which the patient chooses to deviate from the treatment regimen" (Lowry et al., 2005). A number of health behavioural theories have been used in an attempt to better understand why a patient would choose to deviate from their treatment plan; i.e. to better explain intentional non-adherence. These theories include the Health Belief Model (HBM), Self-Regulation Theory (SRT), the Theory of Planned Behaviour (TPB), Self-Determination Theory (SDT) and the Transtheoretical Model (TTM) of stress and coping (Holmes et al. 2014).

1.3.3 Factors associated with medication non-adherence

Medication non-adherence is a multifactorial problem. The World Health Organization (WHO) classified medication non-adherence factors into five subcategories; patient-related factors, therapy-related factors, health-system related factors, disease-related factors, and socioeconomic factors (Brown and Bussell, 2011). To improve adherence, it is important to fully understand these factors by themselves and as a unit to come up with a strategy that coordinates interaction between the different categories (Brown and Bussell, 2011). These factors have been studied widely in the literature (Table 1-1). However, the data from the literature about the factors related to medication non-adherence contradict each other. Some of the references mentioned in Table 1-1 reach different conclusions despite looking at similar factors. This is not surprising with the lack of a standard non-adherence measurement tool, which is described in a separate section below. Another limitation of the literature is the lack of non-adherence studies in

the developing world, the area that is inhabited by most of the world's population. This is perhaps explained by the lack of funding and resources in these countries. However, it is a gap that should be filled before implementing any possible future international solution to the problem of medication non-adherence.

Table 1-1: Factors associated with medication non-adherence identified from the literature listed based on The World Health Organization (WHO) classification

Subgroup	Factors	References
Patient-related factors	• Demographic factors: age, gender, ethnicity, education and marital status • Psychological factors: beliefs, motivation and attitude • Patient-prescriber relationship • Health literacy • Patient knowledge • Unhealthy behaviours • Forgetfulness	Jin et al. (2008); Iihara et al. (2004); Senior et al. (2004); Wild et al. (2004); Kyngäs and Lahdenperä, (1999); Sung et al. (1998); Cooper et al. (2005); Kyngäs (1999); Hernández-Ronquillo et al. (2003); Kiortsis et al. (2000); Ponnusankar et al. (2004); Gadkari and McHorney (2012)
Therapy-related factors	• Route of administration • Treatment complexity • Duration of the treatment • Medication side-effects • Behaviour modification • Taste of the drug • Drug storage	Jin et al. (2008); Baguley et al. (2012); Park et al. (2010)
Health-system related factors	• Availability and accessibility of the treatment	Jin et al. (2008); Lawson et al. (2005)
Socioeconomic factors	• Time commitment • Cost and income • Social support	Jin et al. (2008); Dimatteo (2004)
Condition related factors	• Disease symptoms • Severity of the disease • Perceived health status	Jin et al. (2008); Kyngäs and Lahdenperä (1999); Kyngäs (1999)

1.3.4 Methods for assessing medication non-adherence

The methods used to measure adherence can be divided into direct methods and indirect methods. Each type of method has their advantages and disadvantages; however, none is considered universal, and the choice between them depends on researcher preference and what they are trying to observe (Bosworth, 2012). Indirect methods are more numerous than direct methods and the latter provides evidence of drug administration while the former does not (Lehmann et al., 2013), see Table 1-2 and Table 1-3 for more information.

Table 1-2: Direct methods for assessing medication non-adherence

Method of assessment		Description	Advantages	Disadvantages
Direct Measures				
Direct Observation (Osterberg and Blaschke, 2005) (Bosworth, 2012)		Healthcare provider directly observes the patient while taking the medicine. This method is used in extreme cases where non-adherence is associated with social consequences.	Most accurate measure	Expensive Inconvenient
Biological Indices	Drug or metabolite concentrations in the blood (Lehmann et al., 2013)	Measures the medicine and its metabolites in the blood, plasma and serum.	Proves the ingestion of the medicine.	Used for a limited number of medicines. Provides information for short-term adherence. Expensive and inconvenient. No method standardization. Lab results might take time. Effected by inter- and intra-individual variabilities.
	Drug or metabolites concentrations in the urine (Lehmann et al., 2013)	Measures the medicine and its metabolites that are eliminated in the kidney.		
	Biological markers (Lehmann et al., 2013)	Markers are added to some medicine formulations and then measured by a blood or urine test.	Proves the ingestion of the medicine and minimal inter-individual variability.	Limited number of medicines. Invasive, expensive and inconvenient.
Ingestible event marker (Chai et al., 2015)		Tablet or capsule with a fixed ingestible sensor. The sensor is activated after the pill dissolves in the stomach sending a signal to a skin patch that records the data. The data can then be retrieved by healthcare providers.	Proves the ingestion of the medicine.	Limited number of medicines. Expensive.

Table 1-3: Indirect methods for assessing medication non-adherence

Method of assessment		Definition	Advantages	Disadvantages
Indirect Measures				
Self-Report (Lehmann et al., 2013)	Questionnaires	Multiple adherence related questions that are answered by the patient.	Practical. Less time consuming. Easy to implement. Flexible. Discreet. Reasonable cost Can be conducted with a small number of staff. Easy to distinguish intentional and unintentional non-adherence. Very handy for research purposes.	Tend to overestimate adherence.
	Medication Diary	A diary that is given to the patient to record the dose, frequency and any missed doses.		
	Healthcare provider report	Healthcare provider interpretation of an interview with the patient or by measuring the treatment outcome.		
	Interview with family members	A qualitative assessment of healthcare providers interpretation of a semi-structured interview with the patient's family.		
Electronic devices (Lehmann et al., 2013)		The use of medical devices with a fitted microchip that records every occasion the container is opened or activated.	Allows dose by dose description. Allows identification of changes in adherence and possible triggers. Best predictor of therapy outcome.	Expensive. Does not ensure the consumption of the medicine. Not suitable for all patients.
Retrospective databases (Steiner and Prochazka, 1997)	Pharmacy refills and prescription claims	The assessment of adherence using retrieved prescription information and pharmacy refill claims.	Rich in objective readily available information. Non-invasive. Economical.	No proof of drug consumption. No consideration of variabilities in dosing times. Inability to retrieve over-the-counter (OTC) medication usage. More accurate for chronic treatments.
	Records review	The assessment of adherence by reviewing patient's medical records.		
Pill count (Lehmann et al., 2013)		The assessment of adherence by counting the number of remaining pills in relation to the number of prescribed pills.	Easy to implement. Non-invasive.	No consideration of variabilities in dosing times. No proof of medicine consumption. Inaccurate. False positive adherence.
Clinical outcomes (Lehmann et al., 2013)		The assessment of adherence by measuring disease specific outcomes.	Convenient.	Not suitable for all conditions. Outcome affected by multiple factors.

1.3.5 Medication non-adherence in patients with breast cancer

As shown above, using hormone therapy, i.e. tamoxifen or an aromatase inhibitor, as adjuvant treatment after surgery or radiation has been shown to reduce cancer recurrence as well as mortality rates (Fabian and Kimler, 2005, Early Breast Cancer Trialists' Collaborative Group, 2015). Guidelines originally recommended the use of tamoxifen in pre- and post-menopausal women for 5 years, but studies have since shown better results when tamoxifen is used for 10 years (Davies et al., 2013) and similarly with aromatase inhibitors (Goss et al., 2005). The guidelines in the UK have adapted to the change and since then tamoxifen and aromatase inhibitors have been offered to women for more than five years (NICE, 2018). Yet research has shown a reluctance by some women to fully adhere to such long-term treatment (Hershman et al., 2010). Therefore, it is essential to understand the reasons of poor adherence so that appropriate measure can be taken to help patients.

One of the major reasons of therapy discontinuation is medication side-effects. This was demonstrated by Demissie et al. (2001) who published the first study that covers adherence to adjuvant tamoxifen. Their purpose was to identify the use of tamoxifen, its side-effects and the reasons of therapy discontinuation. The authors collected data from women's surgical records and by conducting computer-assisted telephone interviews at 5, 21 and 33 months after the beginning of the treatment. The study showed that patients who suffer side-effects are more likely to discontinue their therapy and the authors argued that patients who were oestrogen-receptor negative are more likely to stop taking tamoxifen. This study despite having multiple weaknesses, such as measuring adherence by self-reporting (which reflect what the patient thinks about their adherence not the exact adherence rate) and conducting the study during a period of time when guidelines of using tamoxifen were changing, opened the way for other researchers to consider the issue of tamoxifen non-adherence.

Multiple studies have tried to identify predictors of tamoxifen (non-)adherence among women with breast cancer. Owusu et al. (2008) attempted to identify tamoxifen non-adherence predictors by following a cohort of women for 5 years after their first prescription of the drug. From the 961 women in that study, 49% discontinued tamoxifen before completing the 5 years mark. The main non-adherence predictor identified by the

researchers was older age and other factors that are associated with it such as; number of co-morbidities, polypharmacy and cognitive impairment. Also, women who has undergone mastectomy had a better adherence rate than women who had breast-conserving surgery.

Another predictor of poor adherence is patients' lack of understanding about the importance of their treatment. Offering some form of education about their condition and therapy could have a positive effect on adherence rates as shown by Fink et al. (2004) who conducted a study of patients' beliefs and how they affect adherence. Women with neutral or negative beliefs were more likely to stop taking the drug, with the researchers recommending educating patients about the importance, benefits and risks of tamoxifen to improve adherence in the future. This level of communication was shown by Kirk and Hudis (2008) to be missing in many cases. Their study found out that only 44.2% of patient with breast cancer received instructions from their healthcare provider about the importance of taking their medication as prescribed. Discussing the importance of taking oral medications as prescribed during office visits and emphasizing the clinical importance of adhering to the treatment could potentially improve patients' adherence.

Oral anticancer therapy is a long-term treatment. Therefore, studying adherence rates at a specific point in time might not reflect the real issue of non-adherence. The importance of conducting long-term studies in this area was demonstrated by Partridge et al. (2003) who measured adherence in women with primary breast cancer for a period of 4 years after initiating therapy, finding the rate of adherence decreasing gradually year after year. Adherence rate in the first year was as high as 83%, this rate kept on decreasing until it reached as low as 50% by the end of the fourth year (Figure 1-2). Similar results were found by Lash et al. (2006) after collecting their data through patient interviews, medical record reviews and physician questionnaires. Here, 31% of patients failed to complete their 5-year therapy course. These studies show the importance of studying patients' adherence at different stages of the treatment as adherence rates change with therapy progression.

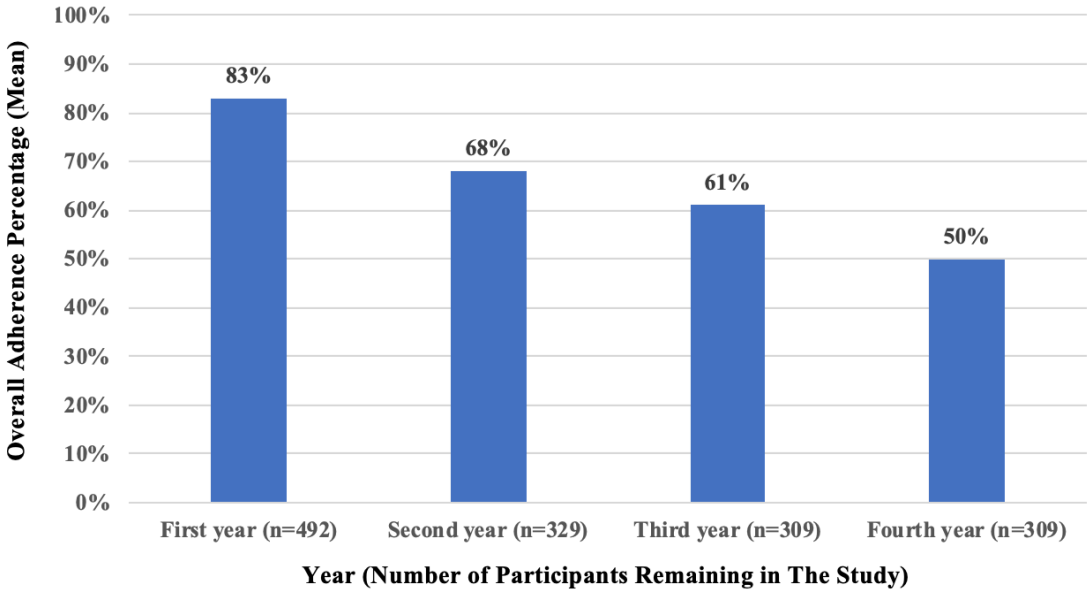


Figure 1-2: Adherence rate decreasing year after year as demonstrated by (Partridge et al., 2003).

Adjuvant aromatase inhibitors show similar patterns of non-adherence found with tamoxifen. Partridge et al. (2008) conducted the first study of adherence to adjuvant aromatase inhibitors, finding adherence decreases with therapy progression, reaching as low as 62% by the end of the third year. Also, the reasons behind non-adherence to aromatase inhibitors are similar to those of tamoxifen. A study conducted by Sedjo and Devine (2010) to identify non-adherence risk factors within a retrospective cohort of 13,593 commercially-insured patients with a prescription claim for an aromatase inhibitor found that young age, medication costs, side-effects, co-morbidities and depression are factors associated with non-adherence. These factors could help in identifying patients at risk of poor adherence to offer them the support and knowledge that could improve their medication taking habits.

Lastly, it is very important to understand the behavioural aspects of non-adherence to hormonal therapy in breast cancer. Atkins and Fallowfield (2006) looked at the problem of poor adherence in breast cancer from a behavioural standpoint trying to identify the main reasons for non-adherence and differentiate between intentional an non-intentional non-adherence. They found that 55% of the 131 participants were non-adherent one way or another to their treatment plan. The identified reasons of non-adherence were numerous, including; younger age and forgetfulness. The finding of the study suggests

that the intention regarding non-adherence is related to health locus of control, which is either internal or external. Patients with an internal locus of control believe that they are in control of their outcome, while patients with an external locus of control blame others or outside forces for events. Patients who intentionally stopped taking their medication viewed themselves as having little control over their own health (external locus of control), while non-adherence in patients with an internal locus of control was mostly unintentional. This study showed the importance of understanding patients beliefs before trying to implement a one-size-fits-all intervention.

1.3.6 Consequences of non-adherence or discontinuation of hormonal therapies

Generally, poor medication adherence is a major problem that is associated with high rates of mortality and morbidity. Moreover, it is associated with an increase in healthcare costs (Iuga and McGuire, 2014). This may be more obvious in the case of oral chemotherapeutic agents where adherence is necessary for successful therapy (Barillet et al., 2015).

Clinicians generally assume that patients are taking the drug as prescribed due to the 'apparent' negative effect of poor adherence to cancer treatments (Johnson, 2015). However, poor adherence is not always intentional, and patients may experience a less than perfect adherence due to unintentional reasons such as; forgetfulness, misunderstanding or adaptation difficulties. This could lead to a misconception from healthcare providers that could potentially result in a change of the drug or its dose, thus, making a possibly successful treatment useless (Given et al. 2011).

Additionally, when patients take less than optimal doses of cancer treatments or stop taking the medication completely, it could cause some severe consequences, such as a reduction in functional abilities, lower quality of life, disease progression and premature death (Johnson, 2015). However, another problem that is raised with oral chemotherapeutic agents is over-adherence. Taking a dose before its time or at the wrong time could potentially cause some toxicities that could lead to some very serious side-effects and adverse events (Given et al. 2011).

Another effect of non-adherence and therapy discontinuation is health resource consumption and financial constraints. Non-adherence and therapy discontinuation are associated with higher clinician visits, higher rates of hospitalization, and unnecessary lab and diagnostic tests. Thus, better adherence could decrease healthcare expenditure through better disease control and less consumption of healthcare resources (Given et al. 2011).

The literature shows variation in adherence to oral anticancer medication in patients diagnosed with breast cancer, with an older study indicating 57% adherence to non-hormone-related medicines (Lebovits et al., 1990), while newer studies focussing on adjuvant hormonal therapy report the prevalence of adherence to range between 41 to 72%, with early discontinuation of 5-year courses being in the range 31 to 73% (Murphy et al., 2012). Rather than being static, it appears that adherence to adjuvant hormonal therapy decreases over time going from 90% in the first year, to 77% in the third and 51% in the fifth years (Makubate et al., 2013). This is despite the knowledge that low adherence to adjuvant hormonal therapy is associated with an increase in all-cause mortality (McCowan et al., 2008), while longer adherence periods lower the risk of mortality and recurrence (Makubate et al., 2013).

Hershman et al. (2010) investigating the effects of non-adherence and discontinuation of adjuvant hormonal therapy identified 8769 women diagnosed with breast cancer taking either aromatase inhibitor, tamoxifen or both. The study showed that 2761 (31.5%) stopped taking the therapy early, and of the 6008 patients that finished the whole 4.5 years of the therapy, 1684 (19%) were non-adherent at one point or another, leaving only 49% of patient who were fully adherent to the therapy for the full duration of the study. The patients were then followed for up to 10 years. A total of 813 deaths occurred within that period, the survival rate at 10 years in women who fully adhered to the regimen was 80.7%, while the survival rate in women who discontinued the therapy early was 73.6%. Also, from the 6008 women who continued the therapy, the rate of survival at 10 years was 81.7% in women who were fully adherent and 77.8% in women who did not fully adhere to the treatment. Thus non-adherence to adjuvant hormonal therapy, like in many other conditions, appears to be a complex problem which is worthy of further exploration with in-depth, interpretive approaches (Donyai, 2019).

1.4 The purpose of this thesis

The purpose of this thesis is to explore, examine and understand women's views and experiences of hormone therapy and their medication-taking practices in the long-term management of breast cancer. Also, to look at the possibility of developing an intervention to improve women's experiences while on the treatment.

1.4.1 Research question

How do women's views and experiences affect medication-taking practices in the long-term treatment of breast cancer with adjuvant endocrine therapy?

1.4.2 Research aim

To develop a theoretical understanding of women's experiences on hormone treatment following a breast cancer diagnosis, using grounded theory.

1.4.3 Research objectives

- Conduct a meta-synthesis examining the existing qualitative studies that have assessed women's experiences with hormonal medication-taking in breast cancer survivorship.
- Develop an in-depth explanatory model of hormonal medication-taking in breast cancer survivorship as it is experienced across the world using grounded theory synthesis.
- Conduct in-depth interviews with women who are breast cancer survivors and who took/have been taking hormone therapy for the long-term management of their cancer.
- Develop and validate an all-encompassing explanatory model of women breast cancer survivors' experiences with hormonal medication in the UK using grounded theory.

The remainder of this thesis is written in the first person, to illustrate my engagement with the research process and, this being a qualitative investigation, my reflexivity throughout the conduct of this work.

Chapter 2: Synthesizing qualitative research

2.1 Introduction

I am going to start this chapter by defining some of the most important terms concerning the philosophy of science. Understanding these terms and the relationship between them is essential in understanding methodological differences and justifying the choice of method used in one's research. The first term to describe is "paradigm", which is defined as "a world view or a set of linked assumptions about the world" (Guba and Lincoln, 1994; Slevitch, 2011). The paradigm is determined by "ontology", in turn defined as "the study of reality or things that comprise reality" (Guba and Lincoln, 1994; Slevitch, 2011). There are different ontological positions one can take in research. The choice of ontological positioning guides our way of processing knowledge, which then links to "epistemology". Epistemology is defined as "a theory concerned with the nature and the scope of knowledge". Epistemology addresses the questions of how we know what we know, what are considered to be the truth and legitimate knowledge, and what is the nature of the relationship between the researcher and what can be known (Guba and Lincoln, 1994; Slevitch, 2011). To answer these questions we must first answer: How can we investigate what we want to know? The final term then is "methodology", a "theoretical and philosophical system that structures the way research is conducted" (Guba and Lincoln, 1994; Slevitch, 2011).

2.2 Philosophical approaches to research: qualitative versus quantitative research

A simple way of examining philosophical approaches to research is to dichotomise the approach as either qualitative or quantitative. The major difference between the two stems from ontological and epistemological differences. The quantitative approach suggests that objective reality can exist with no influence by human perception (Sale et al., 2002; Guba and Lincoln, 1994). It theorizes that ultimate truth exists and that there is only one reality. This is a positivistic approach with a realist, objectivist orientation. Therefore, such an approach theorizes that a phenomenon can be studied by a researcher without him/her influencing it or being influenced by it (Huston and Rowan, 1998; Guba and Lincoln, 1994). This is the opposite of the qualitative approach, which is interpretive

and constructivist in nature. It theorizes that there is no single truth, but multiple realities based on the researcher's interpretation or construction of reality. The reality of a phenomenon in qualitative research is dependent on the researcher's subjective understanding of it (Huston and Rowan, 1998). Therefore, qualitative research is usually conducted with the researcher being as close as possible to his/her subjects of interest.

Quantitative research usually starts with a hypothesis that is deductively supported, confirmed or rejected using a rigid, highly structured method demanding a restricted response from participants. Qualitative research is usually more flexible, allowing a theory to emerge from the study using, for example, open-ended unstructured or semi-structured questions that allow participants to answer freely from their own experiences (Huston and Rowan, 1998).

Another difference between the two approaches is in the sampling parameters. Quantitative approaches use random large sampling to generalize the finding in an experimental setting, answering questions that aim to measure and analyse relations between different variables, such as "how many?", "how much?", "how often?" and "what size?" (Huston and Rowan, 1998). Qualitative approaches, on the other hand, use purposive sampling (recruiting participants based on predetermined criteria) or snowball sampling (participants refer others) with a relatively small number of participant in a natural setting, to identify how a phenomenon that affects everyday life experiences by seeking answers to questions such as "what is happening?", "why is it happening?" and "what variations exist in reality?" (Huston and Rowan, 1998). Other differences between the two approaches are presented in Table 2-1 below.

Multiple reasons make qualitative research an interesting method for researchers as it allows them to:

- Explore participant experience thoroughly
- Explore how meanings are formed and transformed
- Explore areas that are not thoroughly looked at or understood
- Identify relevant variables that could later be addressed quantitively
- Take an all-inclusive approach to studying a phenomenon
- Access to a more fluid and flexible way of identifying the factors influencing the phenomenon

- Exploit the freedom, endless possibilities and serendipity associated with qualitative research
- Connect with their participants and see the world from their point of view
- Play with words and find enjoyment in discovering order in what might at first seem chaotic
- Develop complex relations between themes and reduce uncertainty (Corbin et al., 2014).

Table 2-1: Main differences between quantitative and qualitative research as identified from multiple references (Huston and Rowan, 1998, Guba and Lincoln, 1994, Slevitch, 2011).

Area	Quantitative approach	Qualitative approach
Philosophical positioning	Positivism	Idealism
Influence of researcher	Objective	Subjective
Methodologies	Experimental	Interpretive phenomenological analysis (IPA) Thematic analysis Grounded theory Discourse analysis Narrative analysis
Involvement of the researcher	Distant	Involved
Setting and research questions	Focus on measuring and analysing quantifiable relationships by answering the following questions: How many? How much? How often? What size?	Natural setting to identify the phenomenon and its concepts by answering the following questions: What is happening? Why is it happening? What variations exist?
Sampling techniques	Random sampling with large sample sizes to generalize findings.	Purposive sampling or snowball sampling with a relatively small sample size to explore how people experience and make sense of the phenomenon in question.
Data collection	Statistical analysis Surveys Closed questions Fixed options	Observation Interview (face to face – focus groups) Document analysis Open ended questions (unstructured-semi-structured interview guides)
Approach	Deductive	Inductive
Data analysis	Statistical	Interpretive
Result	Cause and effect	Deeper understanding of the phenomenon

2.3 Methods of qualitative research

In this part of the thesis, I am going to present a brief description of the different qualitative methods used in health psychology. These are: interpretive phenomenological analysis (IPA), thematic analysis, grounded theory, discourse analysis, narrative analysis, and ethnography. Generally, these six methods share a similar progression process in that they start by identifying a problem, which leads to the development of a question, after which researchers start data collection and analysis to produce a final report (Lyons and Coyle, 2016). The differences between the methods are presented in Table 2-2, below.

IPA has a phenomenology, hermeneutics and idiographic origin. Its aim is to explore in detail the personal and lived experiences of each individual participant, not just from the point of view of the researcher but also by how participants themselves make sense of their lived experiences (Lyons and Coyle, 2016; Smith and Osborn, 2015). The sample size in IPA is usually quite small; some studies have argued that a sample of one could even be sufficient in some cases (Lyons and Coyle, 2016). However, usually a study with multiple participants could provide more information and is more suited for a PhD (Lyons and Coyle, 2016). For data collection, the usual method of choice is semi-structured interviews. The results are presented in the final report as a set of themes, with the experience being interpreted by both the researcher and the participants using their own words (Lyons and Coyle, 2016; Smith and Osborn, 2015).

Thematic analysis differs somewhat in that it originates from researchers in the fields of psychology and sociology. Its aim is to identify, analyse and interpret patterns of meaning (themes) by using various types of dataset (Lyons and Coyle, 2016). In this method of analysis, recruitment should continue until reaching code saturation where no new themes could be identified. The results of thematic analysis are usually presented in the form of themes and subthemes, with relations between them explained and illustrative examples offered to support the result of the analysis (Lyons and Coyle, 2016; Braun and Clarke, 2006).

The third method is grounded theory, which originated in the field of sociology. Its aim is to acquire a theoretical understanding of the phenomenon under investigation by

developing an encapsulating theory that explains it (Corbin et al., 2014). Recruitment in grounded theory uses what it is known as purposive sampling, which does not stop until reaching data saturation. Grounded theory studies usually use textual data, semi-structured interviews or observation for data collection (Corbin et al., 2014; Charmaz, 2014). Data analysis follows the systematic approach of open, axial and selective coding until the theory emerges and the all-encompassing theory that is grounded within the data is 'based on solid grounds' (Corbin et al., 2014; Charmaz, 2014). Further explanation of this method is presented in Chapters 3 and 5.

The fourth method, discourse analysis, originated in the field of psychology. Its aim is to explore how a phenomenon is constructed in spoken or any form of written communication, to capture the social implications of the used language (Starks and Brown Trinidad, 2007). The data could be collected in small or large quantities to identify words, sentences and paragraphs and relate them to themes and patterns. This method involves drawing conclusions by presenting the language used and assessing its effect on the broader context under investigation (Starks and Brown Trinidad, 2007).

The fifth method is narrative analysis, which also originated in the field of psychology. It focuses on exploring human life in the form of stories. It uses any resources used to tell a story, such as interviews, videos (including films), music and observational studies (Lyons and Coyle, 2016; Richmond, 2002). Narrative analysis entails capturing the story and recasting it using the researcher's own words, the result being an unfinalized realist tale, told by the participant, that remains unfinished and could change in the future if the participant changes their perception (Lyons and Coyle, 2016; Richmond, 2002).

The sixth and final method described here, ethnography, was derived from the fields of anthropology and sociology. It focuses on exploring the lives of people who share a similar culture or inhabit a similar place (country or company) by collecting data from them and examining their experiences (Lyons and Coyle, 2016). The data is usually collected from primary observations or interviews. The analysis is carried out by generating a description of the life and culture of the group of people under assessment, results taking the form of written reports, videos or photographs describing the social phenomenon in question (Lyons and Coyle, 2016).

Table 2-2: Characteristics of the different qualitative approaches (Lyons and Coyle, 2016; Starks and Brown Trinidad, 2007).

Characteristics	Interpretive phenomenological analysis (IPA)	Thematic analysis	Grounded theory	Discourse analysis	Narrative analysis	Ethnography
Theoretical origin	Phenomenology Hermeneutics Idiography	Psychology Sociology	Sociology	Psychology	Psychology	Anthropology Sociology
Research focus	Exploring in detail participants' individual and personal experiences and how they make sense of them	Identifying, analysing and interpreting the patterns of meaning (themes)	Developing a theory that is grounded on the data	Exploring how a phenomenon is constructed in talk or any form of writing by studying language	Exploring human life	Exploring the life of people that share a similar culture or inhibit a location
Sampling and sample size	Small sample size "sample of one"	Sampling until reaching code saturation	Purposive sampling and theoretical sampling until reaching data saturation	Large or small quantity of linguistic materials	Stories as a sample	A single setting or a group of people
Data collection	Semi-structured interviews	Most types of qualitative data	Textual data, semi-structured interviews and/or observation	Any form of linguistic materials	Any resources used to tell a story, including interviews, videos and observational studies	Primary observations or interviews
Data analysis	Producing themes then clustering them to produce a definitive set of themes	Coding in search of related themes	Open, axial and selective coding	Identifying words, sentences and paragraphs and relating them to themes and patterns	Recasting data to produce a story	Analysing data through description of the life and culture of a group of people
Results	A narrative report of the interpretation of the researcher and participants' explanation of their own experience, using their own words	A report of developed themes and sub-themes with data extracts as illustrative examples	An all-encompassing theory that is grounded on participants' experiences	Conclusions drawn by presenting the language used and its effect on the broader context	An unfinalized realist tale that is still unfinished and could change in the future	In the form of written reports, videos or photographs describing the social phenomenon

2.4 Rationale for methodology selected

The idea I had for my PhD was to try and capture what women go through following a breast cancer diagnosis and how living with hormonal treatment shapes their experiences. The rigidity of quantitative research did not suit my goal because I wanted to develop a thorough understanding of the phenomenon by taking an all-inclusive approach. Qualitative methods provided me with the freedom to examine the endless possibilities that might arise, identify the different factors in play and recognize the complex relations in breast cancer survivors' experiences. They also allowed me to connect with my participants and 'walk a mile in their shoes', capturing their experiences in a systematic manner. For these reasons, qualitative research methods seemed the most suitable approach.

My next step was to review the various qualitative methods described above. Corbin et al., (2014) recommend the use of grounded theory in the following cases:

- When relatively little is known about the phenomenon under investigation.
- When there are no theories that adequately explain the phenomenon under investigation.
- When the researcher is interested in capturing participants' experiences, perceptions and understandings of the world.
- When the researcher wishes to develop a theoretical understanding of the phenomenon under investigation.

Breast cancer survivorship and adherence to hormonal therapy adhere to all these criteria. Grounded theory therefore seemed the most suitable qualitative method to adopt for my research.

2.5 History of grounded theory

Grounded theory was first introduced in 1967 when Glaser and Strauss published their paper entitled *The discovery of grounded theory; Strategies for qualitative research* (Glaser et al., 1967). At the time, this was considered ground-breaking as the authors argued against what they called "arm-chair theorizing", instead emphasizing that a theory should be built from concepts that are developed and derived from actual data. Glaser

and Strauss came from different research backgrounds as the former was a quantitative researcher and the latter came from a symbolic interactionism background (Rieger, 2019). The differences between the two 'planted the seed of division', which came into fruition in 1987 when Strauss developed his own style of doing grounded theory, published in his book *Qualitative analysis for social science* (Strauss, 1987). This divergence led to the demise of the pair's collaborative work.

In 1990, a new partnership between Strauss and Corbin emerged when they published their first joint book, *Basics of qualitative research: Grounded theory procedures and techniques*, offering an accessible and clear description of their grounded theory technique (Strauss and Corbin, 1990). That book is said to have caused a rift between Glaser and Strauss, resulting in the creation of two separate classes of grounded theory (Rieger, 2019). In 1996, Strauss passed away, but Corbin has continued developing their method further, staying true to the key aspects of their early work in the significantly revised third and fourth editions of their book, published in 2008 and 2014 respectively (Corbin et al., 2014).

A variation of grounded theory was later developed by Kathy Charmaz. Following the work of Glaser and Strauss, Charmaz developed constructivist grounded theory in the early 2000s (Charmaz, 2014). In Table 2-3, below, I try to show the differences between the three methodologies of grounded theory. Despite their differences, however, these variations of grounded theory share a lot of similarities, Charmaz identifying the features all grounded theories share in common as the following (Charmaz, 2014):

- Data collection and analysis are conducted simultaneously
- They analyse actions and processes rather than themes
- They use the constant comparison method
- They create codes and categories from the data rather than having preconceived codes
- Categories and codes are developed inductively
- The use of theoretical sampling
- Focus on theory construction
- They identify the variations in categories and processes
- They pursue the development of categories rather than a single topic

Table 2-3: Differences between the three methodologies of grounded theory (Rieger, 2019; Corbin et al., 2014; Charmaz, 2014; Ralph et al., 2015).

	Glaserian grounded theory	Straussian grounded theory	Constructivist grounded theory
Philosophical perspective	Positivist realist	Symbolic interactionist	Relativist subjective
Role of the researcher	Detached observer	Interpretive	Co-creator
Coding stages	Substantive coding • Open coding • Selective coding Theoretical coding • Integrate codes into a theory	Open coding • Line-by-line coding Axial coding • Connecting categories and sub-categories • Use of the coding paradigm Selective coding • Identify the core category	Initial coding • Labelling data with codes Focused coding • Use initial codes to code future data
Analytical tools	Theoretical coding families	The coding paradigm	Use analytical tools from other theories
Strengths	Flexibility Rigorous and results in high-level abstraction Results in greater theoretical completeness	Clear description of the method The use of the paradigm allows researchers to develop a sufficient theory	Develop theory with the participants Allows the discovery of hidden meanings Middle ground between the freedom of Glaserian method and rigidity of the paradigm More descriptive than the Glaserian method
Critique	No sufficient discussion of philosophical assumptions The role of a detached observer is unrealistic Limited ability to find meanings in the data	Rigid Interferes with the researcher's freedom The use of the paradigm could force data into preconceived ideas	Less description than the Straussian method Radical change from the two previous grounded theories
Evaluation criteria	Fit Work Relevance Modifiability	Fit Applicability Concepts Contextualization of concepts Logic Depth Variation Creativity Sensitivity Evidence of memos	Credibility Originality Resonance Usefulness

2.6 Grounded theory method of choice

On the basis of Table 2-3, I decided to adopt Strauss and Corbin's method of grounded theory for my PhD. As a novice researcher, I felt more comfortable using a theory that has a clear and precise description of its process. Another reason is that I planned to start my research by conducting a meta-synthesis of the published qualitative studies. Having done no qualitative work prior to embarking on my own interview study, I wanted to examine the existing literature in order to thoroughly familiarize myself with it and identify with the topic. Doing so is against the Glaser and constructivist methods of grounded theory, both of which urge the researcher to delve blindly into the study, whereas Strauss and Corbin's stance on the matter is a little more flexible (Rieger, 2019). Lastly, the use of the paradigm in Strauss and Corbin's method is more suitable for a novice researcher and for a study such as mine because it helps in identifying the variations in the processes. Adherence is a process, and the way Strauss and Corbin's method proceeds seemed suitable for the task at hand.

For all these reasons, I decided to adopt the Strauss/Corbin method of grounded theory. Any description of data collection, analysis and coding procedure in future chapters is thus based on the Straussian grounded theory method, a precise and elaborate description of which will be presented in Chapters 3 and 5 of this thesis.

2.7 Meta-synthesis

Every research project, arguably, begins with a conventional systematic review. It is a way of identifying the available knowledge in a given field with the aim of recognizing what knowledge is missing in order to justify the necessity of the work to be undertaken. Also, conventional systematic reviews help researchers to locate their research within the relevant field of interest and assess how it might contribute to advancement in the field.

As a novice researcher the term meta-synthesis was new to me, and my original assumption was that it was quite similar to a standard systematic review. However, as I understood more about the complexities of meta-synthesis, I started to recognize the

differences and how much more knowledge a meta-synthesis could potentially bring to a certain area of research.

The term "meta-synthesis" itself was first introduced in 1985 by Stern and Harris to refer to the amalgamation of multiple qualitative studies in order to develop an explanatory theory or model from the findings of similar qualitative studies (Stern and Harris, 1985). A meta-synthesis is not simply an enhanced literature review; if done right, it has the potential to increase knowledge of, and enable insights into, the phenomenon being studied. This highlights the difference between meta-analysis of quantitative studies that aim to increase certainty between cause and effect, and meta-synthesis, which does not rely on the mere polling of data but allows the researcher to look at the available knowledge, question it, deconstruct it and then reconstruct it in a way that provides an all-encompassing theory that could potentially reduce the uncertainty in the field (Dixon-Woods et al., 2006; Thorne et al., 2004; Walsh and Downe, 2005).

Critique of meta-synthesis is still in its infancy, however. Little has so far been written on how to best conduct such a study, and what is written lacks clarity and should not be considered as a guide to follow. Multiple studies have looked at providing guidance and information about the different frameworks, among them Barnett-Page and Thomas (2009) and Tong et al. (2012), but these are not extensive enough and leave a lot of questions unanswered. As I embarked on this research, I was convinced of the ability of meta-synthesis to enrich my knowledge of the field and help me develop a theoretical understanding of the phenomenon I was about to investigate. However, I needed first to develop a closer familiarity with the method through a study of the published literature. Below I provide a summary of the available methods of meta-synthesis research, together with an example from the published literature in which each was used.

2.8 Methods of meta-synthesis

In recent years, multiple methods of synthesizing qualitative literature have emerged, their aim being to develop an interpretive approach to studying the qualitative literature. These methods include; critical interpretive synthesis, grounded theory synthesis, meta-

ethnography, and thematic synthesis. Table 2-4 sets out a brief summary of these methods.

Table 2-4: Summary of the methodologies for synthesizing qualitative literature (Tong et al., 2012).

Methodology	Critical interpretive synthesis	Grounded theory synthesis	Meta-ethnography	Thematic synthesis
Philosophical positioning	Subjective idealism	Objective idealism	Objective idealism	Critical realism
Literature search	Theoretical sampling	Theoretical sampling	Not specified	Systematic and comprehensive
Quality appraisal	Judgement on data's ability to inform theory development	Judgement based on context and usefulness	Judgement based on relevance	Criteria related to the different parts of the paper
Analysis techniques and concepts	Extract data and summarize papers Coding Generate themes	Open, axial and selective coding	Analysing first- and second-order constructs	Line-by-line coding Codes organized into themes
Synthesis output	New theoretical concepts	Generation of a grounded theory	Generation of third-order construct	Themes that offer a new explanation
Example of studies using this methodology	Dixon-Woods et al. (2006)	Kearney (2001)	Smith et al. (2005)	Ridd et al. (2009)

2.9 Justification for using grounded theory synthesis for the qualitative systematic review

As I reviewed the various methods for synthesizing qualitative research, a certain lack of consensus and standardization became clearly apparent, despite the fact that synthesis of qualitative data has increased greatly in recent years and despite the availability of

extensive guidelines on how to conduct qualitative research. A study by Tong et al. (2012) provided a guide on the process of conducting a synthesis of qualitative studies, with the help of published examples. However, the guide is still not extensive enough and leaves many questions unanswered. Specifically, the provided examples lack detail and do not provide enough data for the guide to be considered useful. Simple but essential information such as how to conduct a literature search, how to undertake a quality appraisal of the literature, and what data should and should not be included in the analysis for the different methods, are either missing or ambiguous.

Every method has its pros and cons. However, due to the fact that I was unable to obtain clear and precise guidance on how to conduct a meta-synthesis using any of the available methods, due also to the extensive similarities between the methods, and above all to the fact that grounded theory is the method I chose for the original research I intended to undertake, using grounded theory now (for my meta-synthesis) could, I reasoned, provide me with great insight into the method itself and be considered great training for my later work.

Although I used grounded theory synthesis in my study, I was unable to find instructions on *how* to use it to guide data collection. I therefore decided to use a different method, meta-ethnography, to guide some of my data collection, along with a broad grounded theory approach for the analysis. These two methods of qualitative synthesis share a lot of similarities. Both are used by qualitative researchers interested in the theoretical understanding of a phenomenon; both use only qualitative studies as a source of data; the philosophical positioning of both methods is objective idealism (the existence of a collectively shared understanding); lastly, both methods lean toward developing a theory (Bearman and Dawson, 2013; Tong et al., 2012; Atkins et al., 2008). The methodology of combining meta-ethnography for data collection and grounded theory synthesis for data analysis, together with a step-by-step description of the process, is presented fully in the next chapter.

Chapter 3: "A meta-synthesis of the qualitative literature examining adherence to adjuvant endocrine therapy in breast cancer survivorship"

3.1 Introduction

First, I start this chapter by providing here (see Table 3-1) a few definitions of some key terms I will be using throughout this chapter and beyond.

Table 3-1: Definitions of terms used in chapter 3 (Atkins et al., 2008; Corbin et al., 2014; Charmaz, 2014)

Element	Description
First order construct	Constructs that reflect participants' understandings, as reported in the included studies (usually found in the results section of the article).
Second order construct	Interpretations of participants' understandings made by authors of these studies (and usually found in the discussion and conclusion section of the article).
Phenomenon	In grounded theory, the outcome of interest, or subject.
Context	The location of the event or set of circumstances that makes the person act in the way that they do. In the paradigm model of grounded theory everything (causal condition, actions/interactions, consequences and mediating factors) falls within the context.
Causal condition	The events that lead to the occurrence or development of the phenomenon and answer the question "why do things happen?"
Actions/interactions	The activities and responses that people perform in response to events or problematic situations that occur in their lives.
Consequences	The actual outcome of the action/interaction taken by the person either intended or unintended.
Mediating factors/intervening conditions	These factors either facilitate or constrain the whole process under investigation.
Core category	A central concept or main theme that describes and integrates the different categories in a concise manner.

3.1.1 Background

Although multiple qualitative studies have been undertaken to understand and describe women's perceptions and experiences of a breast cancer diagnosis and its treatment in different global settings, none provide a comprehensive theory to explain all the challenges of long-term medication-taking in HR-positive cases and the resilience needed to continue. In addition, no secondary research has collected, compared and analysed these different studies to develop an all-encompassing theoretical insight of a phenomenon which may well have experiential universality, justifying a review of the global literature. The purpose of this qualitative systematic review and meta-synthesis then was to source, appraise, and synthesise data from existing qualitative studies to develop an in-depth explanatory model of experiences with hormone therapy in breast cancer survivorship across the world. The aim was to use a grounded theory and an interpretivist approach. As detailed in Chapter 2, I chose grounded theory as the method of analysis so that my findings could meaningfully feed into the next phase of my investigation; an interview study which itself aimed to use grounded theory. Grounded theory has its roots in sociology and is based on the notion that concepts grounded in the data can be examined and integrated into a core category (Corbin et al., 2014). It is an interpretivist approach, which is concerned with deconstructing the meanings and of the phenomenon being researched in order to explain why it operates the way it does (Thorne et al., 2004).

3.1.2 Aim and objectives

3.1.2.1 Aim

To source, appraise, summarize and synthesise data from existing qualitative studies to develop an in-depth explanatory model of hormonal medication taking in breast cancer survivorship as it is experienced across the world.

3.1.2.2 Objectives

- Retrieval: To identify all the available qualitative studies covering the topic of adherence to adjuvant endocrine oral medications in breast cancer by conducting a systematic search in PubMed, Web of Science, Cumulative Index to Nursing

and Allied Health Literature (CINAHL), PsycINFO, Wiley Online Library, ProQuest, Taylor & Francis online, ScienceDirect, SpringerLink and Google scholar.

- Appraisal: To critically assess the quality of the identified studies while remaining methodologically neutral using criteria based on those established by Hawker et al. (2002)
- Synthesis: To synthesize the data from the literature by applying a grounded theory approach.

3.2 Method

3.2.1 Database search:

I completed a comprehensive search of the published literature via multiple relevant databases to identify qualitative research papers on the topic of women's adherence to oral hormone therapy in breast cancer; namely; PubMed, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Wiley Online Library and ProQuest. In addition, I searched Google scholar, Taylor & Francis online, ScienceDirect and SpringerLink to identify studies that may not have been indexed in the previous databases. I also scanned the references in the identified articles for relevant studies that I may have missed in the database searches. I conducted the search exercises which were verified by my supervisor Prof. Parastou Donyai. The searches were conducted between 01/11/2017 and 23/01/2020.

I conducted the searches using multiple MeSH terms and related words, such as, qualitative research, cancer, tumor, tumors, tumour, tumours, chemotherapy, oncology, antineoplastic, antineoplastics, antineoplastic drugs, antitumor drugs, antitumour drugs, neoplasm, neoplasia, antineoplastic agents, anticancer agents, antitumor agents, antitumour agents, cancer chemotherapy agents, cancer chemotherapy drugs, chemotherapeutic anticancer agents, chemotherapeutic anticancer drug, anti-carcinogenic agents, anticarcinogenic agents, anti-carcinogenic drugs, anticarcinogenic drugs, anticarcinogens, cancer therapy, cancer pharmacologic therapy, cancer pharmacotherapy, adherence, compliance, nonadherence, non-adherence, noncompliance, non-compliance, medication adherence, medication compliance,

medication non-adherence, medication non-compliance, medication nonadherence, medication noncompliance, medication persistence, patient adherence, patient compliance, patient non-adherence, patient non-compliance, patient nonadherence, patient noncompliance, patient cooperation, oral, oral administration, oral drug, oral drug administration, oral medicine, oral medication, tablets and capsules. These terms were combined to search the databases, in addition to other terms identified from the articles retrieved such as; quality of life, survivor, survivors, survivorship, survivorship care and patient experience. I have provided further detail below.

3.2.2 Studies retrieved and inclusion and exclusion criteria:

I included articles if they were primary research studies, used qualitative methodology, investigated adherence to adjuvant hormonal therapy in the management of HR-positive breast cancer, and were written in the English language. I included papers published in the decade 2010-2019 reasoning this era would provide data most relevant to modern practice. Studies were excluded if not written in English, used quantitative methodology, were reviews, were not specifically about breast cancer or did not investigate adherence to hormone therapy. I have detailed a full search history in Appendix 1 showing the construction of the search queries, the narrowing down of the searches and the final yield from each database. A total number of 582 papers were first identified narrowed to 447 with duplicates removed. The titles and abstracts of these 447 papers were reviewed for eligibility with 81 included in the full-texted assessment, and 57 papers excluded meaning 24 articles were selected for qualitative synthesis. A PRISMA chart showing the search and retrieval process is presented in Figure 3-1 below.

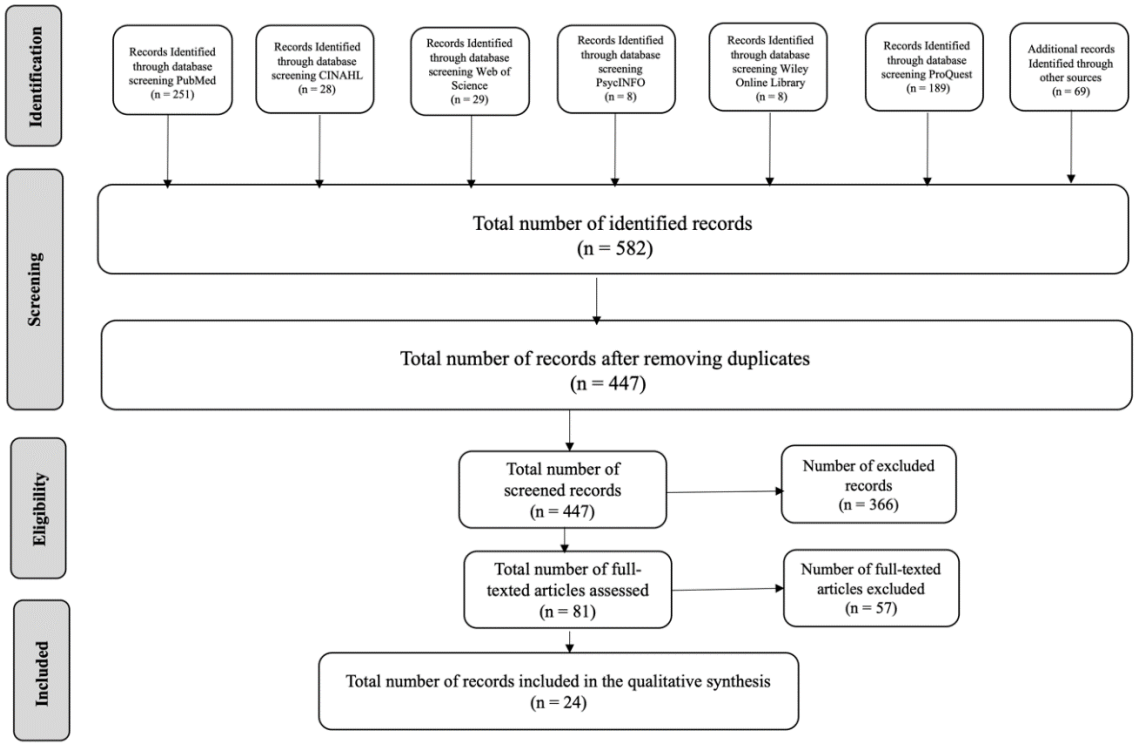


Figure 3-1: PRISMA chart showing the database search and articles retrieved.

3.2.3 Data abstraction and appraisal

I first reviewed the full text of the 24 articles included in my meta-synthesis. I extracted any information about women's adherence to oral anticancer medication for analysis. I created a grid to summarize the studies included in my meta-synthesis. It presents information about the study including the year, the country the study was conducted in, the sample size, the study objectives, the research design and a brief description of the result that shows the themes which I identified (Table 3-2).

I evaluated the quality of each study and compared my ratings with an independent evaluation by Dr. Nilesh Patel (with a discussion to resolve any differences) using criteria based on the work of Hawker et al. (2002). The appraisal involved using nine items on a checklist to assess the quality of different elements of each paper, rating them as good (g), fair (f), poor (p), or very poor (vp) (Table 3-3). The Hawker et al. (2002) tool was designed to provide insight into study strengths and weaknesses rather than offering a cut-off for exclusion of evaluated studies. The quality of the studies included in this

review varied but since the aim was to capture the breadth of experiences, I did not exclude any studies as each contributed something new and different. Thus, the principal determinant of inclusion was utility of the findings. I ensured compliance with the 'Enhancing transparency in reporting the synthesis of qualitative research' (ENTREQ) criteria for this work, as shown in Appendix 2.

Table 3-2: A summary of the studies included in the review

Study No.	Study	Study Location	Sample size	Study Objectives	Data Collection	Data Analysis	Results
1	**Harrow et al. (2014)**	Scotland	30 women	To investigate the experience of women taking adjuvant endocrine therapy and what might influence their adherence	Semi-structured face to face interviews	Constant comparison method	**The eight themes identified in the study are:** Lifeline to being cancer free Doctor knows best Remembering not to forget—got the routine It's a religion Living with the side-effects—I'm still alive Keeping it to themselves —everyone's different No one's ever asked if I'm still taking it Appropriate expertise
2	**Wei et al. (2017)**	Shanghai, China	17 Participants	To explore the differing perspectives of patients and providers and their assessment of supportive care needs in breast cancer patients receiving oral chemotherapy.	A semi-structured interview followed by one or two in-depth interviews	Qualitative content analysis	**The five themes identified in the study are:** The patient–provider discordance in assessing information needs The patient–provider discordance in assessing communication needs The patient–provider discordance in assessing social support needs The patient–provider concordance in assessing needs of symptom and side-effects management The patient–provider discordance in assessing other needs
3	**Van Londen et al. (2014)**	Pittsburgh, USA	14 women	To conduct an investigation of women's experiences related to taking adjuvant endocrine therapy adjuvant endocrine therapy and managing adjuvant endocrine therapy-related symptoms.	4 Focus groups with a semi-structured interview guide	Qualitative content analysis	**The five themes identified in the study are:** Adjuvant endocrine therapy as a non-decision initially Unanticipated symptoms Difficulty making sense of symptoms Frustration in managing symptoms Weighing pros and cons of ongoing treatment
4	**Wells et al. (2016)**	South-eastern, USA	25 women	To evaluate the barriers and facilitators to taking anti-hormonal medications among medically and historically underserved breast cancer survivors within the first 5	Semi-structured interviews	Qualitative content analysis	**The two themes identified in the study are:** Facilitators of medication adherence Barriers to medication adherence

				years post chemotherapy, radiation, and/or surgery.			
5	**Iacorossi et al. (2016)**	Rome, Italy	27 women	To explore the experiences of adherence to endocrine therapy in women with breast cancer and their perceptions of the challenges they face in adhering to their medication prescribed	Face to face semi-structured interviews	Framework analysis in accordance with Ritchie and Spencer's approach.	**The seven themes identified in the study are:** The different faces of adherence Fear of the drug Adherence stimulates the balance of the experience of illness Adherence influences the future of disease Adherence requires paying attention to the person Knowledge seeking Forgetfulness activates the search for functional strategies
6	**Bourmaud et al. (2016)**	France	17 women	To develop and test the feasibility of a tailored therapeutic educational program, with the aim of improving adherence to oral endocrine adjuvant chemotherapy in women with breast cancer.	One-on-one interviews	Mixed qualitative (Qualitative content analysis) and quantitative method	**The five themes identified in the study are:** Poor knowledge of the disease prognosis and the effects of the adjuvant endocrine therapy Anxiety Loneliness and lack of understanding Worry about the occasional but distressing nonadherence Need for skills in side-effect management
7	**Flanagan et al. (2016)**	Boston, USA	14 women	To describe the experience of women with oestrogen receptor-positive breast cancer who are initiating oral adjuvant therapy and to determine what they describe as facilitating and/or hindering this experience.	Semi-structured interviews	Hermeneutic phenomenological design	**The five themes identified in the study are:** Feeling overwhelmed and abandoned despite highly skilled medical care Processing the trauma and putting it in perspective Keeping up the facade while feeling vulnerable Needing to connect cautiously Moving toward healing and being aware
8	**Rust and Davis (2011)**	USA	24 women	To explore the issues of health literacy and medication adherence among underserved breast cancer survivors.	2 focus groups with open ended questions	Grounded theory	**The four themes identified in the study are:** Inequality of access to health information Acquisition of medication information Medication usage and adherence Barriers to access to medications
9	**Pellegrini et al. (2010)**	South eastern France	34 women	To determine how their perceptions of the treatment and their experience of side-effects contributed to their adherence to the treatment.	Semi-structured interviews	Grounded theory	**The three themes identified in the study are:** Conflicting representations about the hormonal/anti-hormonal effects of tamoxifen The need for clarification about the causes of the perceived menopausal symptoms Making sense of a paradoxical situation

10	**Adams et al. (2017)**	Alabama, USA	15 women	To explore the survivorship experience, concerns, and needs of AA-BCS in rural Alabama with the goal of modifying an existing evidence-based breast cancer survivorship intervention for cultural relevance to rural AA-BCS.	Focus groups and Individual interviews	Qualitative content analysis	**The four themes identified in the study are:** Cancer is a secret Perish with lack of knowledge Start with a good prayer life Limited survivorship support and education
11	**Wickersham et al. (2012)**	Pittsburgh, USA	12 women	To describe the medication-taking experiences of postmenopausal women with early stage breast cancer who were receiving the oral hormonal agent, anastrozole.	Semi-structured interviews	Qualitative content analysis	**The three themes identified in the study are:** Perceptions about Anastrozole—"What I Think": Keeping the Boogie Man Away Side-effects and Side-effect Severity—"How It Makes Me Feel": Being Thrown Back into Menopause Day-to-Day Self-Management—"What I Do": Doing It Yourself
12	**Farias et al. (2017)**	Los Angeles, California and Huston, Texas, USA	22 women	To better understand how physicians communicate with breast cancer patients about adjuvant endocrine therapy (AET), we explored, from the breast cancer patient's perspective, dimensions of the patient-provider communication among women who were on active AET treatment.	Semi-structured interviews	Qualitative principles of inductive reasoning	**The four themes identified in the study are:** Information exchange between physicians and patients about AET treatment Decision-making to take and continue AET treatment Enabling patient self-management and monitoring potential side-effects Emotional support
13	**Wouters et al. (2013)**	Netherlands	37 women	To identify the nature of the experiences and beliefs of women treated with endocrine therapy in an attempt to find potential determinants of non-adherence.	Online focus groups and Individual interviews	Hierarchical cluster analysis	**The nine themes identified in the study are:** Conversations with your physician / nurse practitioner Perceived Support Knowledge of endocrine therapy Use of Medicine Efficacy Adverse effects & events Health Coping with Reflection
14	**Brauer et al. (2016)**	Los Angeles, California, USA	27 women	To explore how survivors of early-stage breast cancer,	Semi-structured interviews	Grounded theory	**The ten themes identified in the study are:** Context of transitional survivorship Lack of AI discussion in oncology follow-up care

				age 65 years and older, made decisions about persisting with AIs, including specific challenges as well as attempts to manage them.			Adverse effects as barrier to normalcy Disentangling adverse effects from old age Disentangling adverse effects from pre-existing conditions Weighing up Bearing the AI Avoiding additional medications AI switching Tipping points: physical thresholds and advances in medical research
15	**Cahir et al. (2015)**	Ireland	31 women	To use qualitative methods to investigate influences on adjuvant hormonal therapy medication taking behaviours in women with stage I–III breast cancer.	Semi-structured interviews	Thematic analysis using Theoretical Domain Framework	**The twelve domains identified in the study are:** Knowledge Social influences Social Identity Beliefs about capabilities Beliefs about consequences Reinforcement Intentions and goals Personality Emotion Behaviour regulation Memory, attention and decision processes Environmental context and resources
16	**Cheng et al. (2017)**	Hongkong	19 women	To reveal breast cancer survivors views and experiences of self-management in extended survivorship.	Secondary analysis of the qualitative data derived from a previous study	Qualitative content analysis	**The three themes identified in the study are:** Managing health and well-being Managing emotions Managing roles and relationships
17	**Verbrugghe et al. (2017)**	Belgium	31 women	To give insight into the process of non-adherence and non-persistence by researching influencing factors and their interrelatedness in breast cancer patients taking antihormonal therapy	Semi-structured interviews	Grounded theory	**Factors influencing the process of non-adherence and non-persistence** Experience with the previous trajectory: the context for antihormonal therapy Expectations regarding the impact of antihormonal therapy Impact of the antihormonal therapy and the experience of the follow-up period Perceptions of the antihormonal therapy Social support **The process of non-adherence and non-persistence** Participants experiencing a low impact Participants experiencing a high impact

18	**Moon et al. (2017)**	London, UK	32 women	To understand women experiences of taking tamoxifen and to identify factors which may be associated with non-adherence.	Semi-structured interviews	Thematic analysis	**The three themes identified in the study are:** Weighing up beliefs about the treatment Living with increased risk of recurrence Information and support
19	**Brett et al. (2018)**	Oxford, UK	32 women	To explore factors that influence adherence and nonadherence to adjuvant endocrine therapy following breast cancer to inform the development of supportive interventions.	Semi-structured interviews	The framework approach	**Identified factors associated with adherence were as follows:** Managing side-effects Taking control of side-effects Supportive relationships Personal influences. **Identified factors associated with nonadherence were as follows:** Burden of side-effects Feeling unsupported Concerns about long-term adjuvant endocrine therapy use Regaining normality Risk perception and understanding the risk
20	**Bluethmann et al. (2017)**	Dallas, Texas, USA	30 women	To build on survey results to qualitatively explore survivors' experiences with prescribed adjuvant endocrine therapy to (a) describe appraisal and management of adjuvant endocrine therapy side-effects and (b) deconstruct decisions to initiate, discontinue, or maintain adjuvant endocrine therapy.	Semi-structured interviews	Mixed qualitative (Thematic analysis) and quantitative method	**The four themes identified in the study are:** Initial acceptance of the provider recommendation for adjuvant endocrine therapy Variable experiences with side-effects Risk versus reward Ability to tolerate side-effects
21	**Humphries et al.)2018)**	Quebec, Canada	43 women	To identify women's attitudinal, normative, and control beliefs regarding adjuvant endocrine therapy adherence that could be targeted by an intervention offered in the community pharmacy setting.	Focus groups and Individual interviews	Thematic analysis based on constructs derived from the theory of planned behaviour	**The four themes identified in the study are:** Attitudinal Beliefs Normative Beliefs Control Beliefs Other constructs including: Perceived Risk Anticipated Regret Moral Standards Self-Identity

22	**Ahlstedt Karlsson et al. (2019)**	Sweden	25 women	To provide qualitative data about women's experiences with endocrine therapy after breast cancer surgery.	Focus groups	inductive content analysis	**The three themes identified in the study are:** Creates discomfort Promotes levels of management Causes feelings of abandonment
23	**Lambert et al. (2018)**	Canada	22 women	To explore breast cancer survivors' experiences and perspectives of adjuvant endocrine therapy use to describe how personal, social, and structural factors influence adjuvant endocrine therapy persistence.	Semi-structured interviews	Thematic analysis	**The six themes identified in the study are:** Side-effects Personal beliefs about recurrence and medications Social support HCP relationship Structural factors Balancing quality and quantity of life
24	**Xu and Wang, (2019)**	China	30 women	To describe the connotations of health beliefs about adjuvant endocrine therapy in premenopausal breast cancer survivors in Northeast China and to explore the reasons underlying bad behaviours and influential factors of adjuvant endocrine therapy adherence and persistence.	Semi-structured interviews	Qualitative content analysis	**The six themes identified in the study are:** Cognitions and understanding regarding AET Recognition of illness recurrence and metastasis Behavioural clues for treatment Self-efficacy for AET Demographic factors underlying health beliefs The influence of socio-cultural factors on health beliefs

Table 3-3 Quality assessment of the studies included in the review based on (Hawker et al., 2002).

Study	Abstract and title (1)	Introduction and aims (2)	Method and data (3)	Sampling (4)	Data analysis (5)	Ethics and bias (6)	Findings / results (7)	Transferability/ generalizability (8)	Implications and usefulness (9)	Total
Harrow et al. (2014)	g	f	g	g	g	vp	g	g	g	g = 7 f = 1 vp = 1
Wei et al. (2017)	g	p	g	p	g	p	g	g	f	g = 5 f = 1 p = 3
Van Londen et al. (2014)	g	f	f	g	g	vp	g	g	f	g = 5 f = 3 vp = 1
Wells et al. (2016)	g	g	f	g	f	vp	g	g	g	g = 7 f = 1 vp = 1
Iacorossi et al. (2016)	g	g	g	g	g	g	g	g	g	g = 9
Bourmaud et al. (2016)	g	f	f	g	g	p	g	g	f	g = 5 f = 3 p = 1
Flanagan et al. (2016)	g	f	g	g	g	g	g	g	f	g = 7 f = 2
Rust and Davis (2011)	f	g	g	g	g	vp	g	f	p	g = 5 f = 2 p = 1 vp = 1
Pellegrini et al. (2010)	g	f	f	g	g	p	f	g	f	g = 4 f = 4 p = 1
Adams et al. (2017)	g	f	g	vp	g	vp	g	g	f	g = 5 f = 2 vp = 2
Wickersham et al. (2012)	g	f	g	g	g	p	g	g	g	g = 7 f = 1 p = 1

Farias et al. (2017)	g	f	g	g	g	f	g	g	g	g = 7 f = 2
Wouters et al. (2013)	g	g	g	g	f	f	f	f	f	g = 4 f = 5
Brauer et al. (2016)	g	f	g	g	g	f	g	g	g	g = 7 f = 2
Cahir et al. (2015)	g	f	g	g	g	f	g	g	g	g = 7 f = 2
Cheng et al. (2017)	g	f	f	f	g	f	f	f	f	g = 2 f = 7
Verbrugghe et al. (2017)	f	f	g	g	g	g	g	g	g	g = 7 f = 2
Moon et al. (2017)	g	p	g	f	g	f	g	f	f	g = 4 f = 4 p = 1
Brett et al. (2018)	g	g	g	g	g	f	g	g	g	g = 8 f = 1
Bluethmann et al. (2017)	g	f	g	g	f	p	g	f	f	g = 4 f = 4 p = 1
Humphries et al. (2018)	f	f	g	g	g	p	g	g	g	g = 6 f = 2 p = 1
Ahlstedt Karlsson et al. (2019)	g	f	g	g	g	g	g	g	f	g=7 f=2
Lambert et al. (2018)	g	f	g	g	g	g	g	g	g	g=8 f=1
Xu and Wang (2019)	g	p	f	p	g	f	g	f	f	g=3 f=4 p=2

(1) Abstract and title: Did they provide a clear description of the study? **(2) Introduction and aims:** Was there a good background and clear statement of the aims of the research? **(3) Method and data:** Is the method appropriate and clearly explained? **(4) Sampling:** Was the sampling strategy appropriate to address the aims? **(5) Data analysis:** Was the description of the data analysis sufficiently rigorous? **(6) Ethics and bias:** Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between research and participants been adequately considered? **(7) Results:** Is there a clear statement of the findings? (**8) Transferability or generalizability:** Are the findings of this study transferable (generalizable) to a wider population? **(9) Implications and usefulness:** How important are these findings to policy and practice? **Criteria: g = good; f = fair, p = poor; vp = very poor.**

3.2.4 Data analysis:

I completed the data analysis in consultation with my first supervisor. Despite publications covering the topic generally (Eaves, 2001; Kearney, 2001), as inferred in Chapter 2, on closer scrutiny no guidance detailed *how* to undertake a grounded theory synthesis of data using existing publications as the data source. Therefore, I shaped my own methodology, drawing heavily on the work of Atkins (2008) and using previous grounded theory expertise within the supervisory team (Almutairi et al., 2018; Ibrahim et al., 2016).

My aim was to deconstruct the findings of the retrieved studies in order to reconstruct them within a grounded theory framework. To do this, I read each study in detail first then I extracted all of the participant quotes evidenced within the original studies to form a dataset of quotes (within the retrieved studies) from women relaying their experiences with hormone therapy following the initial treatment of their breast cancer.

I began the analysis by identifying first order constructs relating to these quotes. To do this, I organized the quotes (n= 801) along a treatment timeline, to span experiences from: receiving the initial prescription (n = 169), to treatment continuation (n = 506), to treatment cessation (n = 87). Ambiguous quotes (n = 39) were excluded. To minimize the impact of preconceptions, I wrote my own interpretation of each quote without reference to the original paper. I then compared my interpretations against the original authors' (second order construct) which offered further explanation and context. This allowed the creation of novel constructs that were informed by interpretations made by the original authors, creating new superordinate groupings.

I then transferred the quotations and interpretations to the NVivo software (v11) and further analysed these using open, axial and selective coding in line with grounded theory methodology to develop the categories (Corbin et al., 2014). Using the paradigm model, causal conditions, actions/interactions, consequences and mediating factors were mapped for each of the categories. Finally, I created an overarching theoretical scheme to interrelate the categories within one core category to conceptually encompass and explain the collective experiences of the participants of the retrieved studies (see Figure 3-2).

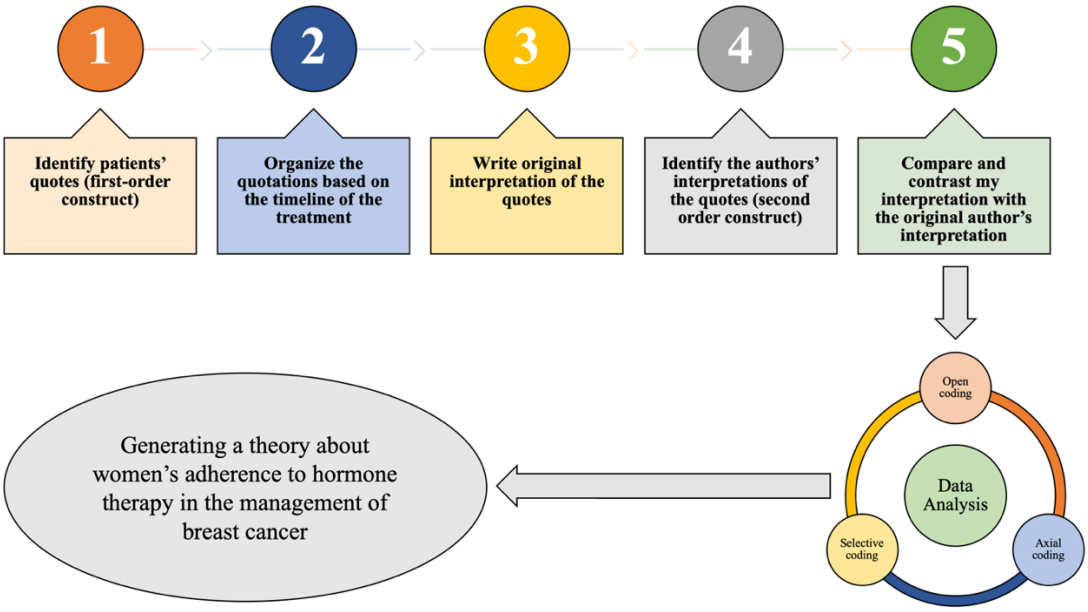


Figure 3-2: The meta-synthesis process

3.2.4.1 Open coding

Box 3-1: Summary of the open coding process

Level 1: Open coding

- Breaking the data apart, one quotation at a time.
- Identifying the low-level concepts that describe the raw data.
  - Brainstorming.
  - Questioning the data.
  - Making constant comparison[s].
  - Reflective thinking.
- Deciding on a set of possible categories (higher-level concepts).
- Discussing the findings with my primary PhD supervisor.

As mentioned above, quotations were organized based on the timeline of the treatment they related to. To be more specific, all quotations relating to the start of the treatment were grouped together, those relating to the adherence stage and experiences with the treatment were grouped together, and those relating to the end of the treatment stage were also grouped together. I started by open coding the first group of quotes, those related to the start of the treatment.

As mentioned in Chapter 2, I adopted the Strauss and Corbin grounded theory method. The open coding process requires a good deal of brainstorming and thinking outside the box, the aim being to capture the hidden as well as obvious meanings of the quotations in order to arrive at concepts that capture them. These concepts, defined as low-level concepts, are then used to create higher-level concepts (categories). These categories need to be based on the solid foundation provided by the lower-level concepts derived from and reflective of the data (the quotations).

I started by reading the quotations multiple times to make myself as familiar with them as possible, then began developing the concepts based on the general ideas the quotations were trying to convey. I next went through the quotations in a more detailed manner, coding line by line and sentence by sentence to be sure no statement was missed and that all ideas were associated with a conceptual label, these concepts reflecting my understanding and interpretation of the quotations. However, they were at this stage provisional, and I remained open to the idea of going back and changing them if I came up with a more appropriate code.

After arriving at the low-level concepts I went back to the data and I started interrogating it with a view to identifying the higher-level categories, asking such questions as "what is going on here?", "Why?", "How?" and "Where?" These questions helped me to identify with the quotations and take my coding to a deeper level by understanding the perspective of the participants, empathize with them and "walking a mile in their shoes".

Another part of the open coding process is constant comparison. As I was coding, I repeatedly checked the codes for similarity and difference. This allowed me to identify the dimensions and properties of each code and thus differentiate the concepts one from another. While doing this I wrote memos to capture my thinking process, reporting my feelings upon reading the quotations, both to capture the emotions I thought the quotation was trying to express and to justify my decisions in choosing the concepts (see Table 3-4).

This process was then carried out in a similar manner to code the quotations relating to the other parts of the treatment timeline. The outcome was a set of codes which I then grouped under a set of categories that capture the data as shown in Table 3-5 below.

Table 3-4: Examples of the open coding process.

Raw data	Concepts	Categories	Memos
"Maybe he did tell me everything, but I also knew I wanted to live. I didn't want to take a chance on not doing what the doctor told me not to do."	Accepting the medication Necessity of the treatment (not a choice) Trust in your doctor Being overwhelmed by the information	Acceptance Trust	The participant viewed the medication as a necessity not an option, and decided to believe in her doctor and adhere to their recommendation without asking. The participant does not remember what the healthcare provider told them in the first meeting. Why? Being overwhelmed. Too much information?
"Even if I know it is supposed to do me good, I still wonder, if it cures me on one side, is it not damaging me on the other side?"	Understanding the mechanism of action of the treatment Lack of trust in the treatment Understanding the side-effects of the treatment Fear of the possible side-effects of the treatment	Knowledge about the treatment (confusion) Trust Fear	The participant mistrusted the treatment and despite its benefits still worried about possible side-effects. Doubts about the treatment? Fear of the side-effects? Being aware of the medication mechanism of action?

"I need to take care of me, but, when you haven't done that so well, you do need some guidance. I don't know how to do it in a way that is meaningful to me. I feel sort of lost… abandoned. Who is going to help me figure this out? If I knew how to do it, I would have done it already."	Recognising the transition into a new stage of the treatment Patients' need of information Not receiving the right information about the treatment Lack of emotional support Refocusing their lives	Knowledge about the treatment (confusion) Support	Participant recognised this time (initiating adjuvant endocrine therapy) as a good time to change. However, the lack of hospital visits and contact with healthcare providers made them feel lost and abandoned. The quotation clearly shows the participant feeling lost and in need of support and guidance.
"After the previous treatments, I wanted to put it out of my head and go on with my life. But when I buy new clothes, I have to buy a bigger size, which confronts me with that goddamn disease. I want to leave this chapter behind and be like before. I do not think I will ever be the same again, and that is very hard to accept."	Recognising the transition into a new stage of the treatment Refocusing their life Going back to normal life before cancer	Feeling normal	The participant recognised the transition after finishing the initial stage of the treatment and wished only for normalcy. However, the effects the treatment had on her body were a reminder of what she had had to endure and left her still feeling a patient. She wanted to feel as before and forget what she had gone through, but had started to accept that she would not be the same person again and that cancer had changed her.

"To me, endocrine therapy was just the next step in the sequence of surgery, chemotherapy and radiation therapy. When I started using endocrine therapy, I thought I had gone through the hardest part of my treatment and I considered endocrine therapy as a protection for the years in the near future. Although I still feel the same about that, endocrine therapy has a big influence on my life. On the positive side, I have not metastatic cancer or recurrent breast cancer. The difficult consequences of tamoxifen and later also Arimidex were the severe depressive episodes. I could not adjust to them, whereas I had accepted many other adversities. My oncologist convinced me to continue."	Recognising transition to a new stage of treatment Living with the side-effects Fear of cancer recurrence Continue living cancer free Accepting the medication Issues during the treatment Trust in your doctor	Acceptance Fear Adapting to the treatment Trust	The participant recognised the transition to a new stage of the treatment. She also recognised the protective properties of the treatment. Although she thought the treatment would be easier to endure than it actually was, she saw the positive in that it continued to protect her by preventing recurrence. She talked about her inability to adapt to the treatment, due above all to episodes of depression. She had talked to her healthcare provider and been persuaded (by necessity, fear of recurrence, and trust in her healthcare provider) to continue the treatment.
"They said that it would remove the, I can't remember the name it's something, oh dear, they did tell me what the Letrozole did and I can't remember what it removes but then if that is removed it can cause brittle bones, which is why I've got the other tablets. They told me that I did have brittle bones and that I could if I fell I could you know break quite a lot so they prescribed the	Side-effects management Issues during the treatment Patient need of information	Knowledge about the treatment (confusion)	The participant had been told about what Letrozole is and what is does, though she couldn't quite remember the information at the time of the interview. She remembered being told that the treatment could have the side-effect of causing brittle bones. She was later told that she indeed had brittle bones, and that if she fell she could break a lot of bones in her body, so was prescribed alternative medication. She was not told in advance about how serious brittle bones could be and

alendronic. They didn't tell me how bad the brittle bones were; I asked the doctor and he said 'no I don't have that information'."			when she asked the doctor was not given any sufficient information.
"But it's like you're damned if you do and you're damned if you don't. It's that worry if you don't take it, oh God, if they find something again then I think it's because I didn't take the tamoxifen. But on the other hand it's living with all these side-effects on it."	Living with the side-effects Fear of cancer recurrence Continue living cancer free Fearing the possibility of regret	Acceptance Fear	The participant talked about the dilemma of whether to continue the treatment and suffer the side-effects, or stop it and take her chances with the cancer coming back. She described it as choosing between two bad options. Due to her fear of regret, and having no one to blame but herself if cancer came back, she felt driven to continue on the treatment.
"Just before I started using endocrine therapy, I got a brochure and I read it carefully. I don't think I discussed the information of the brochure with my oncologist. I spoke with him later when I was already using it and experienced side-effects. I have a need to gain knowledge you know. When I am concerned about something, I'll try to find information about my concerns and if at that point I do not understand the information I ask my oncologist or primary care physician. However, my primary care physician often needs to consult my oncologist, so that does not work out very well."	Other sources of information Issues during the treatment Patients' need of information Lack of appropriate support during the long-term treatment phase	Knowledge about the treatment (confusion)	The participant talked about receiving information and reading it carefully before starting the treatment. However, she did not at the time discuss the information with her oncologist. When she started to experience side-effects, she wanted to learn more and began looking through other sources of information. When her search raised questions that she could not find answers to, she talked to her healthcare providers. When she did so, her primary healthcare providers usually consulted with the oncologist before giving answer about anything cancer-related, something the participant did not like. (Lack of knowledge or not wanting to interfere in any other healthcare providers work).

“I think once you have cancer you start to think, ‘Is this mets to the bone, or is this mets somewhere else... or is it a side-effect from the medication’ … when I take medication, I try not to read the side-effects unless I’m having problems and then I go to the side-effects and say, ‘Ah, yeah, maybe this is it’. But when I started... in my hips, and it was at night and I was having trouble sleeping, I just decided that... this [anastrozole] wasn’t for me.”	Continuous lingering Adverse effects disentangling Severity of the side-effects Knowledge vs. ignorance Reasons to stop the treatment	Continue feeling like a patient Negative aspects Giving up	The participant talked about how cancer made her fear the spread of the disease or the development of other types of cancer. She talked too about things getting entangled and her not knowing what is actually causing what. She also talked about her preference for not seeking out information about side-effects until she started to experience them. She talked about her experience with anastrozole and how severe the side-effects were, to the extent of affecting her sleep; she therefore decided to stop the treatment.
“I know I should be taking them but there's no point because I'm not enjoying life on them. I might as well be dead I thought as feeling like this. Physically, mentally, just totally. I feel great and I'm very happy with my decision because I can't see the point in prolonging life if you're miserable and you have no quality of life, and that’s how I felt on the tablets. I'm getting back to what I used to, what I was like before they put me on the tablets and I feel so much better.”	No quality of life Prioritizing quality of life Preferring death over the treatment Going back to normal life before cancer	Different priorities Giving up Feeling normal	The participant did not enjoy life on the treatment and could not see the point of prolonging a miserable life, prioritizing quality of life over quantity of years. To her, death seemed a better option than the treatment, leading her to stop taking it. Since doing so she had felt happier, more energetic and like her old self, which was her main priority.

Table 3-5: A list of the lower-level concepts and the higher-level concepts which they were grouped under.

Concepts (lower-level concepts)	Categories (higher-level concepts)	Category criteria
Accepting mortality Accepting the medication Acknowledging feelings	Acceptance	Into this category fall all concepts related to accepting the treatment and the health care plan, in addition to those relating to accepting that death is part of life and that fear of it is normal and natural.
Successful initial treatment of cancer Commitment to finishing the treatment Adhering to the physician's advice Trying not to forget the treatment	Commitment	All quotations relating to the participant moving into a new stage of the treatment and showing commitment to seeing it through no matter what (including the side-effects that have to be endured), with the ultimate goal of keeping cancer at bay and preventing recurrence.
Fear of cancer recurrence Fear of forgetting the treatment Fear of possible side-effects Fear of the treatment Fearing the possibility of regret	Fear	All fear-related concepts fall into the 'fear' category. This includes fear of cancer and its recurrence, fear of the treatment and its side-effects, fear of forgetting to take the treatment and about how this might affect their future health, and fear of the possibility of regret should they actively decide to skip a dose, take a drug holiday or decide to stop the treatment completely.
Preferring death over treatment Faith and religion as a barrier Other priorities over treatment	Giving up	Quotations about giving up and deciding to stop the treatment before reaching the end.
Being overwhelmed with the received information Knowledge vs. ignorance Lack of knowledge about the side-effects Looking for new research Not receiving the right information about the treatment Other sources of information Patients' need of information Poor knowledge of the disease and treatment The patient's use of clinical terms	Knowledge about the treatment (confusion)	All patient quotations relating to knowledge, information and understanding about their treatment and/or its side-effects. Also, all quotations relating to patient preference for either knowing as much as possible about their condition, or the need to know based only on what they experience. Finally, quotations relating to the sourcing of such information, how patients felt upon learning it, how it was communicated to them and how it made them feel.

Understanding about the side-effects of drugs Understanding how their drug act Importance of communication Hormone therapy vs. the contraceptive pill		
Continue living cancer free Continuous lingering Normalcy Other people meddling	Continuing to feel like a patient	All quotations relating to the patient wanting to feel normal again and go back to their life before cancer.
Recognizing the need to change Recognizing the need to focus on themselves Recognizing transition to a new stage of treatment Learning from others' experiences Lifestyle modifications Self-motivation Alternative medicine Side-effects management	Adapting to the treatment	All quotations relating to an additional or a dynamic action that the patient describes in an attempt to better adapt to their new life.
Patients' need for support Rejecting peers' support Lack of appropriate support during the long-term treatment phase Lack of emotional support Asking for help Owe it to everyone Relationship with family members The follow-up visits Pharmacist's role during the treatment	Support	All quotations relating to patient's need for support from family, friends, co-workers and professional healthcare providers. Also, it covers all quotations that relate to the kind of support provided, and whether or not this affects them, positively or negatively. It also includes quotations relating to relationships, families and the different effects these things have on patients' journeys. Finally, quotations relating to the role of different healthcare providers during the course of the treatment and the follow-up visits.
Cancer treatment taking precedence over other conditions Dealing with other conditions	Other conditions	Quotations relating to other, co-existing conditions, and how these affect or were affected by the breast cancer diagnosis.

Adverse effects disentangling		
Going back to normal life before cancer Delay starting treatment until regaining control Living with the side-effects Normalcy Refocusing their lives Feeling much better	Feeling normal	Quotations relating to the patient's desire to feel normal again and to how cancer has affected their life and changed it.
Life appreciation Maintaining a positive attitude Positive experience with the treatment Living healthy and keeping quality of life	Staying positive	All quotations about positivity, the need for a positive attitude, and positive changes made by participants to improve their own experience.
Putting on a front Questioning life's meaning Asking for help Goal conflict Not receiving the right information about the treatment Poor knowledge of the disease and treatment Everyone's cancer experience is different	Feeling lost	All quotations relating to participants feeling lost and confused about their treatment, side-effects, relationships, goals and having to hide what they are going through.
Knowing someone who has had a bad treatment experience Issues during the treatment Expensive treatment The need to pay for treatment No quality of life Severity of the side-effects Sexual life	Negative aspects	All quotations conveying participants' negative perception of the treatment fall into this category, covering such aspects as the expense of treatment, the severity of side-effects and others' negative stories about the treatment.

Lack of trust in healthcare provider Lack of trust in the treatment Trust in your doctor Overprescribing Only peers will understand	Trust	Quotations relating to participants either trusting or doubting their healthcare providers, the treatment and the healthcare system as a whole. Also those about support groups and help provided by peers.
Necessity of the treatment (not a choice) Commitment to finishing the treatment The treatment is the most important It will be difficult to stop Believe in the treatment	Necessity	Women's answers about the necessity of their cancer treatment and their commitment to continuing it in order to prevent recurrence.
Trying not to forget the treatment Took it long enough Reasons to stop the treatment Part of my daily routine It is not a big deal to miss a dose It will be difficult to stop Filling the prescription Ease of taking the medication drug holiday Adherence is never asked about Adhering to physicians' advice Reaching the end of the line	Adherence	All quotations relating to adherence, adherence issues, non-adherence, filling in the prescription, and techniques to always remember to take the treatment as prescribed.
Benefits vs. harms Given the chance to decide Given the choice to stop	Decision-making	All quotations relating to women having to make a decision and their thought process in this connection.
Prioritize quality of life Delay starting treatment until regaining control Death over treatment Goal conflict Going back to normal life before cancer	Different priorities	All quotations about women having different priorities besides taking the treatment, what these priorities are and the reasons behind their way of thinking.

Going through the treatment again Knowing someone who has had a bad experience with the treatment Having other priorities over the treatment Refocusing their lives		

3.2.4.2 Axial coding

Box 3-2: Summary of the axial coding process

Level 2: Axial coding

- Identifying the causal conditions, actions/interactions and consequences.
- Developing the relationship between the different factors of the paradigm.
    - Brainstorming.
    - Questioning the data.
    - Making constant comparison[s]
    - Thinking reflectively.
- Mixing deductive and inductive coding to create the categories that constitute the paradigm.
- Creating the diagram that shows the links and the flow of the process under investigation.
- Discussing the findings with my primary PhD supervisor.

Axial coding in Straussian grounded theory is about integrating concepts into what is known as the paradigm. One thing worth mentioning here is that the paradigm is just a tool to help researchers cluster the data and link it. It is not something to fixate on, just as the coding itself should be done without obsessive attention being paid to the different parts of the paradigm.

> "Something is missing when analysts think of coding only in terms of the specifics of the paradigm, and that something is the eloquence that gives qualitative research its soul." (Corbin et al., 2014)

The paradigm consists of causal conditions, actions/interactions and consequences, which I have defined at the beginning of this chapter. These parts of the paradigm allow researchers to interrogate the data in a way that is consistent with any process or activity in our daily lives. The questioning is done in the form of, "If *this* happens, I do *this* in the anticipation that *this* will happen". The paradigm helped me develop the relationships between the various concepts and categories arising from the open coding process. As already mentioned, the coding process is by no means linear in nature. Open coding goes hand in hand with axial coding, starting from establishing simple relationships and connections between the data and moving forward until complex relationships begin to show themselves (see Figure 3-3). One more thing I started to identify at this stage are

the mediating factors or intervening conditions. Factors influencing the whole process and making the participant experiences either easier or more difficult started to emerge from the data, helping me make sense of them in piecing together the final story. Due to the gathered information being organized based on the treatment timeline, the findings were grouped into three main models based on that timeline as follows: 1) *guided by the doctors: accepting the long-term prescription*, 2) *balancing priorities: adhering to the long-term treatment* and 3) *taking a chance: stopping the treatment early*. The full models are presented in the Results section of this chapter.

Context: Completing the acute stage of treatment for breast cancer		
Causal conditions	**Actions/interactions**	**Consequences**
Lack of information and uncertainty about the medication (necessity, efficacy, safety and mechanism of action)	Women looking for information else-where (through specialized websites, specialized forums or from other survivors)	Being well informed by receiving the correct information (not looking for information in the wrong places and correcting the misconceptions about the treatment) Being wrongly informed about the medication (side-effects, mechanism of action, efficacy and safety)

Figure 3-3: An example of the use of Strauss and Corbin's paradigm model.

3.2.4.3 Selective coding

Box 3-3: Summary of the selective coding process

Level 3: Selective coding

- Refining the theory.
- Linking the categories around a core category.
- Examining the created theory and core category against the collected data to make sure the theory is all-inclusive.
- Checking for any gaps in logic.
- Explaining the phenomenon under investigation.
- Discussing the findings with my primary PhD supervisor.

The next step in the analysis process is selective coding. The selective coding process is about bringing everything in the analysis under an umbrella called "core category". The criteria provided by Strauss for coming up with a core category are the following (Corbin et al., 2014):

1- Sufficiently abstract, tying all concepts together.
2- Appears frequently in the data, with all pieces of information leading back to it.
3- Logical and consistent.
4- Can be used in future research.
5- Grows in depth and power as it starts linking all different categories together.

Integrating the various parts of the theory was the most difficult step of the analytical process, especially since the models were divided into three different paradigm models based on the treatment timeline. To come up with it I had to go back to the dataset to re-examine the quotations and my own memos. The main thing that kept appearing in the data was the necessity of the treatment and how perception of it differed between the different participants. Their beliefs about and perception of their treatment make it possible to separate them into two groups: adherent and non-adherent participants. One technique mentioned by Corbin and Strauss is the use of metaphors and idioms to capture the experience researchers are trying to portray in their studies (Corbin et al., 2014). So, I took this main theme and started looking at different idioms in the literature that capture and reflect my understanding of the participants' experiences. This led me to the core category, "Hobson's choice or a horned dilemma?". In the Results section of this chapter I am going to describe this core category and how it encapsulates the whole participant experience. I checked the theory I had constructed against all original data to validate it and make sure it captures everyone's story.

3.3 Results:

The findings are grouped into three main categories based on the timeline of the treatment as 'guided by the doctors: accepting the long-term prescription', 'balancing priorities: adhering to the long-term treatment' and 'taking a chance: stopping the treatment early' (see Figure 3-4). These three categories are described in detail below:

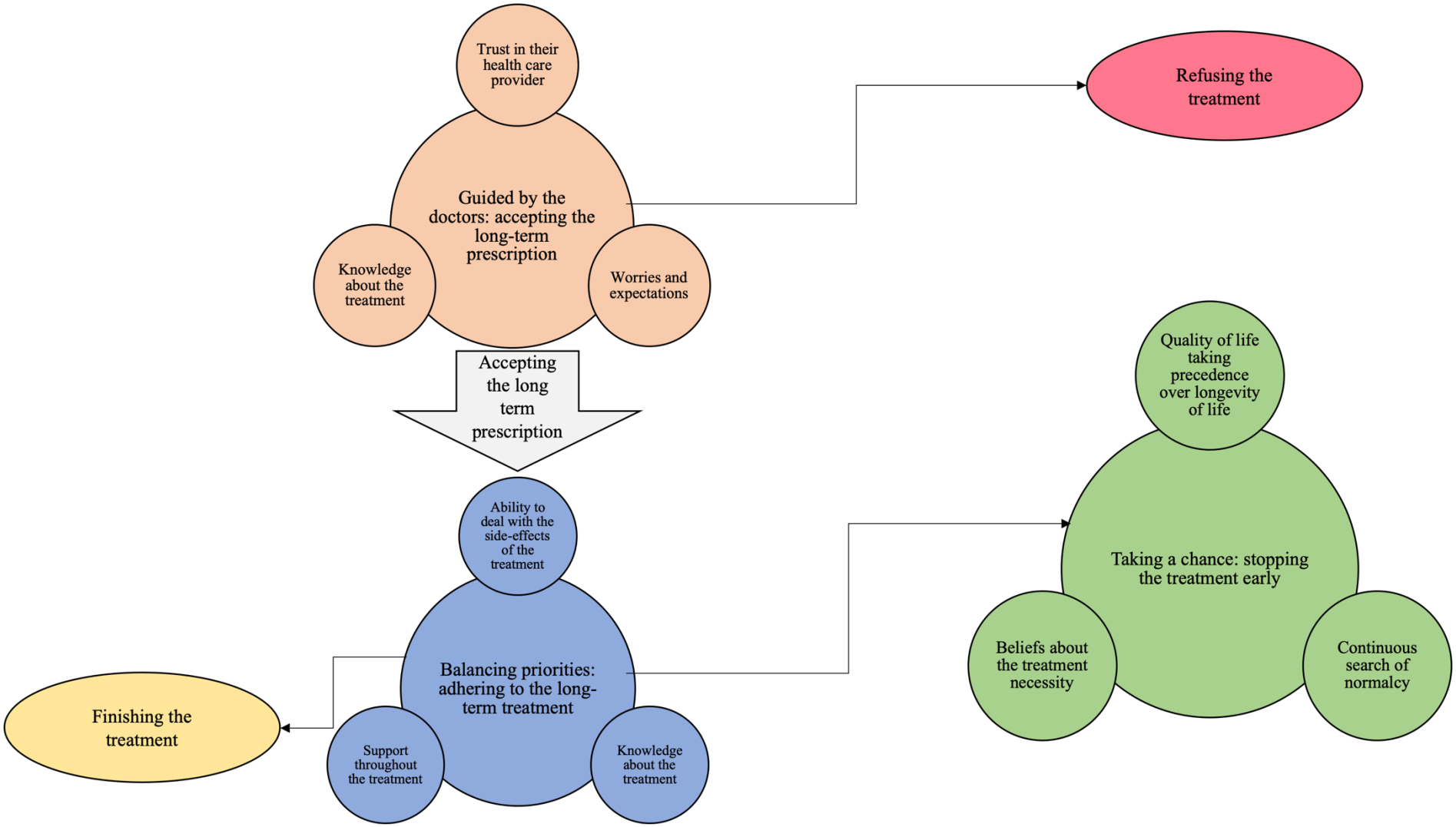


Figure 3-4: Representation of the treatment progression and the three developed paradigm models.

Context: Completing the acute stage of treatment for breast cancer

The care of women being treated for breast cancer, in the UK guided by the National Institute for Health and Care Excellence (NICE), involves treating women with chemotherapy, radiotherapy, or surgery at the acute stage and with long-term treatment with a hormonal drug given as appropriate.

Trust in their healthcare provider

Causal conditions	Actions/interactions	Consequences
Transitioning into a new stage of breast cancer treatment Being overwhelmed by information provided all at once Fear of cancer recurrence Fear of possible side-effects of the new treatment Lack of specific information and uncertainty about the medication (*necessity, efficacy, safety and mechanism of action*) Feeling vulnerable The memory of difficult experiences during the initial stage of the treatment (*at a personal level, professional level or emotional level*)	Having a consultation about the medication where it is prescribed Accepting or deferring the treatment *(dependent on e.g. trusting their healthcare provider advice, awareness of the necessity of the medication, the level of stability in family and social life, emotional stability and support, desire to continue living cancer free, co-morbidities, need of normalcy)* Women taking care of themselves Women looking for information elsewhere (*through specialized websites, specialized forums or from other patients*)	Going along with the hormonal prescription Delaying the hormonal treatment Transitioning into the long-term treatment phase with ease (*trusting the treatment and finding the necessary support*) Having difficulties transitioning into the long-term treatment phase Being well informed by receiving the correct information (*not looking for information in the wrong places and correcting misconceptions about the treatment*) Being wrongly informed about the medication (*side-effects, mechanism of action, efficacy and safety*) Fewer hospital visits (*less communication with healthcare providers*) **Guided by the doctors: accepting the long-term prescription**

Worries and expectations

Knowledge about the treatment

Figure 3-5: The paradigm model for the category 'Guided by the doctors: accepting the long-term prescription'

3.3.1 Theoretical category 1: Guided by the doctors: accepting the long-term prescription

Women with breast cancer are initially treated with surgery, radiotherapy and/or chemotherapy, depending on their diagnosis. After this stage, those diagnosed with HR-positive breast cancer are prescribed tamoxifen or an aromatase inhibitor as hormone therapy treatments to take long-term, essentially to prevent recurrence. The first step in the long-term management of HR-positive breast cancer is therefore the prescription of the hormonal treatment (see Figure 3-5). Illustrative quotes are imbedded in the text below and a list of all quotes is in Appendix 3.

3.3.1.1 Causal conditions:

After completing the acute stage of the treatment of breast cancer, women are prescribed a hormonal drug if appropriate for the long-term management of their condition. Women are asked to start the treatment immediately, which not all patients do. Transitioning into a new stage of cancer treatment is more difficult for some women. They can feel overwhelmed by the information they receive at this stage of their treatment. For example:

> "I try to remember everything ... on the first day. But I can't remember anything when things happen. I really hope we can get the information gradually." Study 2
> "I am afraid of receiving too much information. And I just need the information that encourages me and assures me that I'm still alive." Study 2
> "Maybe he did tell me everything, but I also knew I wanted to live. I didn't want to take a chance on not doing what the doctor told me not to do" Study 3

Fear of the recurrence of cancer can be very imminent and affects the decision making. Some people also worry about the possible side-effects of the medication they are being prescribed which influences their decision to accept the medication. For example:

> "I see my tamoxifen as the lifeline to being cancer free." Study 1
> "My feeling towards the pill is that this is preventing the cancer from coming back. I'm putting all my hopes in, that tiny little pill is going to keep me well for the next five years." Study 15

> "When I was told I had breast cancer I thought 'right, this is it, I have three children at home, I want to be around for them for a lot longer'. I don't want the cancer to come back, I have all my faith in tamoxifen." Study 15
>
> "Obviously at the beginning you are a little scared, even for the possible side-effects" Study 5
>
> "The doctor frightened me so much with all the possible side-effects that I asked myself, where are you going with this treatment?" Study 6

Altogether, the data highlight that women need more information about their condition and its treatment at this stage and are sometimes uncertain about the necessity of the hormonal medication. A sense of vulnerability is also apparent in the data, where women are suffering emotionally. This makes it difficult for some to transition into the next stage of the treatment. The acute stage of treatment would have been difficult for many, on a personal, emotional and physical level. Therefore, some women report the need for a break before transitioning to a new stage. For example:

> "One told you, "Take this," and this is it. No one explains . . . anything [to you]. One told you, "This treatment is to prevent recurrence." But eventually, you don't know why and how it could stop recurrence." Study 6
>
> "The most important thing is to not feel alone...especially at the beginning because one feels lost" Study 5
>
> "I would definitely recommend psychological support, especially in the first stage of the disease as it is terrifying" Study 5
>
> "It's like your last infusion is ending, and you can see everyone thinks, 'OK, finally [you're] back to normal.' It feels like they are ready to pounce on you. I'm thinking, like, really, I need a minute. I've been to hell and back." Study 7
>
> "You know what they say, fake it to make it, but I'm a wreck on the inside." Study 7

3.3.1.2 Actions/interactions:

A consultation with the prescriber is a prerequisite to receiving hormonal medication. A range of factors influence a woman's decision to accept and start the treatment or delay

it. Factors such as their trust in their healthcare provider, having stable and supportive family or friends, emotional and psychological stability, suffering from multiple co-morbidities and women's desire to continue living cancer free. For example:

> "I must admit I take it – if they [doctors] say it's a good idea I'm very much […] I think because my experience has been so positive with them [doctors] I've not come away doubting anything." Study 19
>
> "I knew there was not an option that I was not going to take It. so I think It was just such a positive reinforcement when it was given to me, like this is what you do for five years to block the estrogen, and I just went with It. I didn't second guess it." Study 20
>
> "Just as I was feeling ready to talk, no one was there to listen. Care changes; friends move on to the next big thing." Study 7
>
> "After the previous treatments, I wanted to put it out of my head and go on with my life. But when I buy new clothes, I have to buy a bigger size, which confronts me with that goddamn disease. I want to leave this chapter behind and be like before. I do not think I will ever be the same again, and that is very hard to accept." Study 17

At this stage of the treatment, women take on more of the responsibility for their own care. This means less hospital visits, less communication with healthcare providers, and some women find this difficult to adjust to. Sometimes women do look for information elsewhere. They try to identify other sources of information that could provide them with the knowledge they did not get from healthcare providers. In addition, women look for the newest information about their treatment. They look for the latest clinical trials and published studies about breast cancer and the medication they are about to use.

> "I look for information on my own...they just told me to take that drug because there was a 45% possibilities not to face other problems and nothing more! Then one compares and discusses with friends, on the Internet, and evaluates the effects that can be attributed to the drug" Study 5
>
> "I need to take care of me, but, when you haven't done that so well, you do need some guidance. I don't know how to do it in a way that is meaningful to me. I feel

sort of lost . . . abandoned. Who is going to help me figure this out? If I knew how to do it, I would have done it already." Study 7

"I need to work with someone who could help me redefine who I am, what's important . . . really, in every aspect of my life." Study 7

"And so, at that point, I'm done with my radiation, the chemo, with the surgery, with the whole deal. I'm kind of on my own a little bit…. You're also trying to get your footing…you feel like you don't have all the structures we talked about before, so now you're winging it, and that's scary." Study 14

"one pill per day for five years" or "up to 10 years because of "new research." Study 12

3.3.1.3 Consequences:

Ultimately, as the current model is detailing the experience of women who begin their hormonal treatment, the main consequence here is for women to receive the first prescription. Some women view the hormonal medication as a necessity for the success of their overall treatment, thus, transit into the long-term management stage with ease. Other women delay the start of the treatment. They report facing difficulties transitioning to the next stage of the treatment, so they delay taking the medication until they regain personal control. For example:

"The way I see it is that this is my chance. It may be a small chance but I see it as being a chance to diminish my chances of its returning..." Study 1

"For 5 years I will take that tablet, because if it is the barrier between getting it and not getting it, I will take that tablet. I am adamant that I will take it for the 5 years. I will definitely take it for 5 years until they tell me to stop." Study 15

"Over this last year, I did everything I was supposed to. I have other worries I need to take care of before starting that." Study 7

"I just keep refilling the prescription. . . . I said I was taking it. They seemed happy I had no symptoms. . . . I mean, I planned to start it, and I did. I just needed to get other [health-related] things in order, but after all they have done for me, I could never just say I didn't start yet. As I am saying this to you, I know how crazy it

sounds. I could not imagine what it would be like for them to hear me say it." Study 7

Women receive information about their condition and treatment from a variety of sources. A big transition is observed when women start the long-term management of breast cancer. If these women are well informed, they report that they find it easier to adapt to this transition, accept the long-term treatment and take good care of themselves. For example:

> "Education is necessary in order to understand the importance of it all" Study 5
> "I need my questions answered in whatever way that she [the oncologist] can statistically, because she can't say personally what's going to happen to me. And then I'm going to have to decide which [AET treatment] I want." Study 12

3.3.1.4 Mediating factors

I identified various factors as having an effect on the prescription phase of the treatment. These factors either facilitate or constrain the process of accepting the hormone therapy and are referred to as "mediating factors" or "intervening conditions" in line with the grounded theory methodology. The mediating factors which I identified in this model are 'trust in their healthcare provider', 'knowledge about the treatment', and 'worries and expectations'.

The first mediating factor relates to women's trust in their healthcare provider. Women who trust their healthcare provider find it easier to transition from the initial, acute stage of the treatment to the later long-term management phase. The level of trust varies from one woman to another and has a great effect at this stage of the treatment. Women who trust their healthcare provider have a tendency to not worry too much about the treatment's side-effects, necessity, efficacy and safety. They believe that their healthcare provider has their interests at heart, as well as the knowledge and experience to decide what is best for them. These women tend to listen to their healthcare provider and try to adhere fully to their recommendations and advice. Whenever they are faced with an issue or have questions, they try to reach out to their healthcare provider and seek an answer from them, rather than go looking for information in what may be the wrong places.

Women who do not trust their healthcare provider, on the other hand, have a more difficult transition. They do not have the support needed to calm their fear of cancer recurrence and of the treatment and its side-effects. As a result, such women are at this stage of the treatment vulnerable and in need of support.

The second mediating factor is knowledge about the treatment. This is a complicated factor that tends to differ from one woman to another. While some believe in the virtue of knowledge, others take the view that ignorance is bliss. Some women want to receive as much information as possible about their medication, its side-effects, necessity, safety, efficacy and mechanism of action. They want to be well informed and ready to face anything that might happen in the future. These women need the knowledge that will help them make decisions and take actions. When they do not receive the information they require or do so in a way they are unable to process, they start looking for it elsewhere, which raises other issues caused by misinformation or misunderstandings. The second group of women, by contrast, do not want to receive lots of what they think is unnecessary information. They fear that knowing too much information about the treatment and its possible side-effects will overwhelm them and negatively affect their adherence to the treatment plan. When they ask questions, they are looking for hope and support.

The third mediating factor is worries and expectations. After women go through the initial stage of the treatment and move to the long-term management stage, they have many worries. Women at this stage expect complete remission and think of hormone therapy as the treatment that will secure this outcome. However, fear of cancer recurrence is well observed in the data and does affect women's medication-taking habits. Some women expect the treatment to be difficult and to require a lot of changes and adaptations. Without even trying, they think of the treatment as an enemy and expect a lot of problems, which is a very negative mentality to start the treatment with.

Another aspect that is well observed in the data is a fear of side-effects from the treatment. The side-effects of hormone therapy are in some cases very severe and make living with them very difficult. Some women expect the side-effects to happen to them and question

the necessity of the treatment, while prioritizing other aspect of their life, thereby negatively affecting their medication-taking habits.

These three mediating factors identified in this study act not separately but in combination, interfering with each other throughout the prescribing process (Figure 3-6). The most dominant factor is women's trust in their healthcare provider. If women are able to find the knowledge and support they seek from their healthcare provider and trust them fully to answer all their worries, the prescribing process as a whole has the potential be a much better experience.

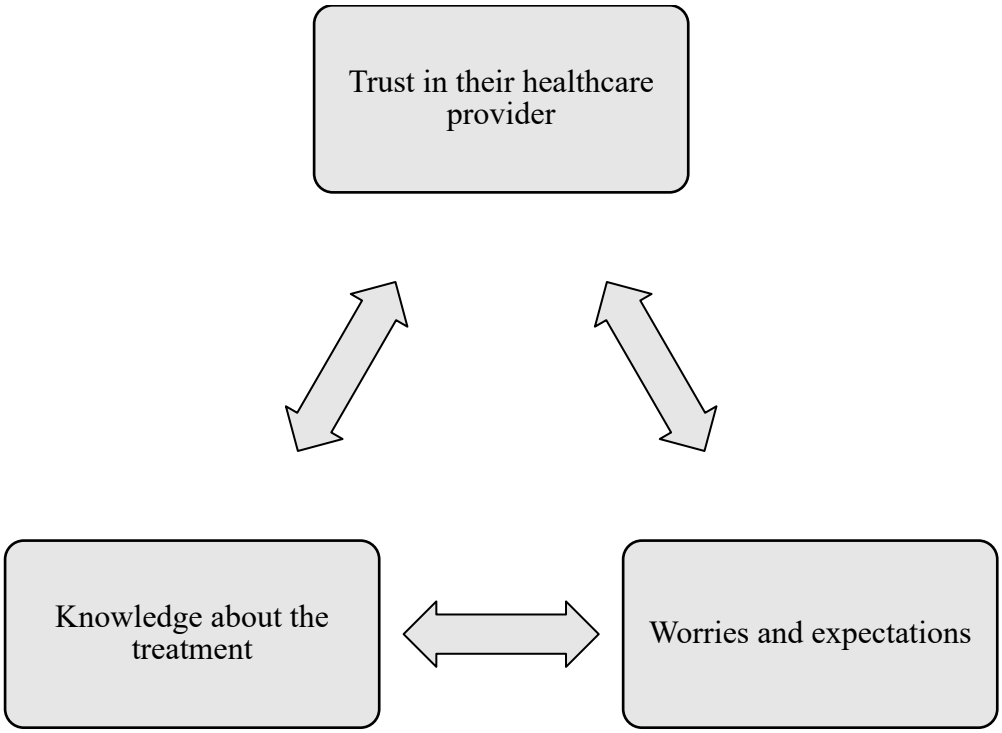


Figure 3-6: The relationship between the three mediating factors identified in the category 'Guided by the doctors: accepting the long-term prescription'.

3.3.1.5 Treatment refusal

Although most women in the included studies accepted the treatment eventually, some did not. Many factors played a role in their decision. The most-quoted reason was their fear of the potential side-effects. This was clearly apparent from the available data, as shown below:

> "I don't take everything they give me." "If it has too many side-effects, I don't take it." Study 8
>
> "I didn't take anything because I was afraid of the side-effects." Study 8
>
> "Most importantly, I read that tamoxifen causes cancer of the uterus. The contraceptive pill? I never took it because it was said to be carcinogenic. The hormone treatment for menopause? I did not agree to taking it either, for the same reason. Cancer I already had it once, and that was enough, so I refused to take tamoxifen!" Study 9
>
> "My main reasons for not taking it were the side-effects that you read about, you're straight into a medically induced menopause. The mood swings, depression and I would be afraid that you would get hooked on medication, there's so many people out there being overly medicated." Study 15
>
> "The effect may not be so obvious, and the medicine can lead to serious side-effects, such as uterine cancer, vaginal bleeding. I was frightened by these side-effects, so I didn't dare to take the medicine." Study 24

Another reason for women's refusal to take the treatment was having other priorities, an example being the wish to start a family:

> "I had a girlfriend, who helped me during the disease. She had kidney cancer four years ago while she was pregnant. She had a splendid baby, and no longer had cancer. It's a bit mysterious, cancer, isn't? After the disease, my husband and I had to go ahead. We thought: 'If that is the case, there's no point in taking tamoxifen and wasting five years.' Tamoxifen did not seem vital to me, nor very reliable. Our wish to have a child was very strong, we did not agree with waiting." Study 9
>
> "I was so scared, so I didn't take it, because I haven't had a child yet. I'm afraid I would not have a baby if I took the medicine. To be frank, I am already sick. If I am unable to have a child, I'm afraid my husband would divorce me." Study 24

Another woman prioritized her work and thought of it as the most important aspect of her life. She felt that taking tamoxifen would prevent her from being the best she could

be and that refusing the treatment would allow her to live free of debilitating side-effects and to meet any deadline she might have:

> "I feel tamoxifen wouldn't have suited my lifestyle to try and do what I have to do every day. It's fairly hard, when you're on a time schedule with a job and you have your targets to reach in the day at a certain time. I just wanted a quality of life for myself, even if I was only to get the last year the way I've got it, being medication free, for me personally it would have been a better quality than having to take it." Study 15

Quality of life was another priority, some women refusing the treatment because they believed living free of side-effects to be more important than living longer while potentially suffering as a result of their treatment:

> "Well that was my big thing about taking Aromasin. If I have to take it for five years and my quality of life is so bad, do I want to take it? These are probably the last good five years of my life − I'm 60. Do I take it and have all these side-effects?" Study 3
>
> "I feel tamoxifen wouldn't have suited my lifestyle to try and do what I have to do every day. It's fairly hard, when you're on a time schedule with a job and you have your targets to reach in the day at a certain time. I just wanted a quality of life for myself, even if I was only to get the last year the way I've got it, being medication free, for me personally it would have been a better quality than having to take it." Study 15
>
> "If I have to take something I wanted something that doesn't interfere with my level of functioning as much as possible. I said feck it, you want the best quality of life and you want to be able to live your life as normal as possible." Study 15

Some women felt that they were given a choice to either take the treatment or not, due to their type of cancer and its low chance of recurrence. So, in their unique circumstances, they decided that taking the treatment was not worthwhile.

> "If the results came back from the oncotype test to say that I had a high-risk aggressive cancer I would have been on it straight away. Also, I don't have the genetic cancer gene. That's how I weighed it up, those two things. I said right they're not getting any medication into me. It was up to me then how I was going to handle it rather than it handling me, and that's the way I looked at it." Study 15
> "The doctor told me to take the medicine, but I think the surgery went very well, and it is not necessary to take medicine, so I did not take it." Study 24

Another reason some women decided against continuing was exhaustion from the initial stage of the treatment:

> "What I really thought was I don't think I want this. That's what I was thinking. I think mainly it's that I wanted to be finished with the treatment, I'd had the operation, I'd had the chemo, I had the radiotherapy but I just wanted to finish with it. As far as I was concerned that was the end of it. I didn't want to be still caught into the system." Study 15

Another reason some women decided not to go ahead with the treatment was that they had heard others tell either of their bad experience with it or of actually sticking with the treatment for its full duration only to suffer from breast cancer again, down the line. One woman told the story of her cousin suffering such a recurrence despite sticking to hormone therapy.

> "A cousin of mine was taking hormone therapy for breast cancer and ten years later the cancer came back in the other breast. So what did she achieve? Nothing. I know women eight, ten years down the line that are not taking it and they're fine." Study 15

One woman told of basing her decision not to take the treatment on the experiences of others who had not had success with hormone therapy despite adhering to it.

> "I did hear through different groups, through listening to other people's stories, that most of the people that had taken it below fifties didn't have a very high

> success rate with it. One was terminally ill, my own sister she was dead at 39 and another lady's daughter died around 41 and all three were on tamoxifen, so that made up my mind." Study 15

Another woman told the story of a friend who went through a similar path to hers, refused hormone therapy and went instead with alternative medicine, ending up living for several more years.

> "My friend died of breast cancer. She'd a similar surgery as my own, the chemo, the radiotherapy and all that. She gave up the medication and went alternative instead. She got six or seven years so if I get to 70 that's alright you know. That's the way I feel about it, who knows after that." Study 15

These accounts demonstrate the effect on the women participants of word of mouth and the experiences of others who have gone through similar circumstances. In some cases these accounts drove women's decision-making, the available data showed that if a woman had known someone who had had a bad experience with hormone therapy, it was liable to make them refuse the treatment completely.

Context: Accepting a prescription for adjuvant hormone therapy

Women are prescribed tamoxifen or aromatase inhibitors as adjuvant therapy after surgery, radiation or chemotherapy for breast cancer. Guidelines recommend the use of tamoxifen in pre- and post-menopausal women for five years and could be extended more than that if needed. Also, the extended use of aromatase inhibitors after the initial five years after diagnosis has been encouraged in post-menopausal women.

Ability to adapt to the side-effects of the treatment

Causal conditions	Actions/interactions	Consequences
Trust and belief in the treatment and its necessity versus fear of treatment and its side-effects	Looking for appropriate support from specialists, GPs, nurses, pharmacists, support groups, family and friends	Adhering to the treatment despite being surprised by the challenges and the severity of the side-effects (i.e. finding adherence to be more difficult than originally thought)
Wanting to continue living cancer free (realizing necessity of the treatment) and fearing cancer recurrence (anticipating regret)	Looking for other sources of information	Forgetting to take the treatment as prescribed occasionally or taking a drug holiday to manage side-effects
Receiving correct information about the treatment and side-effects in advance	Trying to manage the side-effects	Committing to finishing the whole duration of the treatment
Need for knowledge vs preference for not knowing (psychological burden)	Experimenting with alternative medicine	Putting up with side-effects of the treatment
Severity of side-effects experienced or feared (*e.g. menopausal or psychological)*	Discussing the possibility of changing the hormone therapy medication	Suffering from the side-effects of the treatment
Ease of access and availability of professional support and perceived their trustworthiness	Modifying life to adapt to the treatment and its side-effects *(e.g. quitting work due to lack of energy, downsizing, changing other routines such as sport/exercise, social activities, traveling, housework and frequency of sexual intercourse, taking up healthier eating habits)*	Restricting social activities
Wanting support from family, friends, co-workers and other patients.	The use of coping mechanisms to ease the experience (e.g. active coping and self-motivation, seeking physical and emotional support, maintaining a positive attitude, meditating, acceptance, humour)	Side-effects of the treatment, old age and other medications get entangled
Obligations to family to get well and owing it to others to live	Incorporating medication into routine and watching for changes in usual routine	Cancer and feeling ill linger throughout the treatment
The perception of the treatment (positive or negative)		**Balancing priorities: adhering to the long-term treatment**
Continue feeling as a cancer patient throughout the treatment, even though being told that they are cured, and cancer is completely gone		
Ability to always remember to fill the prescription and take the medication as prescribed		
Changes in the patient's usual routine		
Expense of the medications (insurance issues)		

Knowledge about the treatment

Support throughout the treatment

Figure 3-7: The paradigm model for the category 'Balancing priorities: adhering to the long-term treatment'

3.3.2 Category 2: Balancing priorities: adhering to the long-term treatment

Adjuvant endocrine therapy should be taken for 5 years or more so when treatment begins the onus is on the woman to adhere to the regimen by taking the medication by mouth every day. Certainly women's views about their treatment and its side-effects influence their adherence, but these views can change during the treatment period (see Figure 3-7).

3.3.2.1 Causal Conditions:

Women with breast cancer are prescribed tamoxifen or an aromatase inhibitor as adjuvant therapy after their surgery, radiotherapy or chemotherapy. Patients are then asked to adhere to this treatment for a long duration (5 years and more). Some see the medication as the route to prevent recurrence of their cancer. They trust the treatment and believe in its therapeutics benefit, despite any side-effects. Thus, they decide to adhere to the prescribed treatment. Others adhere to the medication even if they don't fully believe in its preventative power, even if it is to avoid future regrets should their cancer return. For example:

> "Never missed it, never, it's in my head you know it's something I have to do" Study 1
> "The tablet, I take it. . .also because fear is fear and I have a son to raise" Study 5
> "That's very important, that pill... I want to live... I want to stay healthy." Study 11
> "At this stage I don't think anything would really happen if I stopped, but at the same time it is not a risk I want to take." Study 15
> "But it's like you're damned if you do and you're damned if you don't. It's that worry if you don't take it, oh god, if they find something again then I think it's because I didn't take the tamoxifen. But on the other hand it's living with all these side-effects on it." Study 18
> "If I don't take it I feel a bit guilty. I mean to say that if my cancer comes back, I'll say well there, you didn't follow it." Study 21

Women's' knowledge about the treatment and its side-effects is a very important factor at this stage of treatment. Patients being surprised by treatments side-effects is a factor

that is mentioned multiple times in the data. Some expressed their need for information in advance so they can deal with the side-effects when occur. Others are surprised by the severity of the side-effects despite knowing about them in advance. Having the knowledge in advance, would have enabled them to manage the treatment better, a situation they blame on their healthcare providers. For example:

> "There has to be somebody helping us with those things Why am I going off of this [AET] in 5 years? We need a theory about what this Arimidex is doing to us I worked in the medical field I really don't understand It stops estrogen, ok, that's all I know I think that would really be helpful to help people understand why they're taking it (symptoms)" Study 3
>
> "Well you need to know the side-effects, that's the first thing because you want to know how you can pace your day and what to expect throughout that day and what to do" Study 4
>
> "I think they have explained too little about side-effects. They have actually minimized them, which makes them worse than I imagined them to be. Now I have to learn to deal with it after I have experienced them and this is very difficult." Study 17
>
> "If someone had said to me, these are the side-effects that other women report – say 20% of women have this side-effect, and if you get it come back and we can help you with it, then that would have been great. It's a lack of information that's the problem." Study 19
>
> "I would have liked more information to prepare for the side-effects. I was given lots of information about the side-effects of chemotherapy and how to manage them, but I wasn't expecting the side-effects of AET. So perhaps that made it worse." Study 19

Women also worry about the unknown long-term side-effects of hormonal medication. They continuously question if the medication is doing more harm than good and whether it is worth risking the side-effects. While most patients need information to better adhere with the treatment plan, some patients preferred not knowing too much detail because having more information, including about side-effects and survival rates would put more stress on them. For example:

> “I’m very afraid of this treatment I’m scared” Study 6
> “I suppose it’s mad that I’ve put my trust in a doctor and a drug that I probably should know more about but the problem is I would have worried myself sick if I knew all of the bad things.” Study 15

Experiencing the side-effects of the medication is another major causal condition but this experience affects people differently. Some patients are not affected too badly by the side-effects, and others who do experience severe side-effects, do nonetheless think of this as a small price to pay for the promise of the medication. However, some deal less well with the side-effect and look for ways to manage them. The side-effects mentioned in the data are either physical (such as; menopause, hot flashes, loss of libido, vaginal dryness, joint and bone pain, weight loss, fatigue and memory loss) or psychological (such as; depression, issues with body image, mood disturbance, anxiety and insomnia). The way patients adapt and manage the treatment and its side-effects is also mentioned in the data and differs from one case to another. For example:

> “There are days that all of you is in pain, all the body… A pain that you don’t know what is hurting And it is so horrible … you try to be still so it doesn’t hurt You can’t cook, you can’t clean, you can’t even bathe because…the pain is in all your body” Study 4
> “You learn to live with it...as it could save my life" Study 5
> “I take it before going to bed because I fear nausea I said to myself, “If you have nausea, you’re going to be asleep” Perhaps it’s going to be better” Study 6
> “I wanted to be able to do something for myself. I wanted to be able to adapt and have some way of coping with the side-effects. I started by eating more healthily. It was a way of taking back control.” Study 19

Another causal condition is the availability and ease of access to professional support. Specialized physicians, general practitioners (GPs), nurses and pharmacists are all involved in this stage of the treatment. Some patients complain about a lack of access to their cancer specialist. Some also feel unsupported by others and left to figure things out by themselves. Patients experiences with GPs are variable; some like consulting with

their GPs while others do not. The latter feel that GPs lack the knowledge and/or desire to deal with any breast-cancer related issues. Some talk about their experience with their pharmacists. While some did not know that pharmacists could provide help, others who had some mixed opinions about this. For example:

> "Nobody's asked me about it since And the Doctor [GP] knows that I'm on it, but we never discuss it." Study 1
>
> "The relationship isn't there I wouldn't have thought about going to see the pharmacist to talk about my side-effects with any medications, I go to the GP about that" Study 1
>
> "Yes, they've got a little consultation room that you can go in privately and talk to them [Pharmacist] and, you know, I think these women are very smart and they know their drugs" Study 1
>
> "Don't get me wrong. My GP is lovely. But they don't know much about treatments for breast cancer. I'd rather talk to someone at the hospital." Study 19

Women who have a good relationship with their healthcare provider try to adhere to their advice. Some qualities help build trust, such as; a trustworthy demeanour, respectable, realistic, positive, nice, not condescending and prominent in the field. Other factors that improve the patient-provider relationship include knowing the patient and having up-to-date knowledge. Not seeing the same physicians can also be problematic. For example:

> "For me establishing personal relationship with the oncologist was so important" Study 5
>
> "He [oncologist] knew me by my name, my face. When I came in, it was like they treated you like you were a person and not just cattle coming through^. "He used to call me his most delicate patient." Study 12
>
> "I would have preferred to see always the same oncologist, I had difficulties because when doctors changed I found myself thinking I had to start again, to find problems, misunderstandings..." Study 5

Support from other people such as family members, friends, co-workers and support centres (other patients) is also important at this stage of treatment. Patients who report a

good relationship with their loved ones and receive their continuous support and encouragement adhere better to the treatment. In contrast, patients who lack this support report difficulty with the treatment and with the management of side-effects. Some blame themselves for being unable to take care of their family like they used to before the cancer, for example to perform housework, to be there for their kids and have sexual relation with their partner. For example:

> "You really can only go so far with, even your husband They only want to hear what's going on for a couple of minutes (symptoms)" Study 3
> "He [husband] is brilliant. He's very understanding – he has been with me 100% through everything. He has gone to hospital appointments with me but he just worries about how I feel." Study 19
> "My husband and two children are a motivation for me to live." Study 24

Not everyone wants to receive support from their friends and co-workers who likely don't understand their experience. They believe that only other patients will understand their predicament, thus, seek support and encouragement from support centres. Receiving support can also create a sense of obligation to others such that patients feel they owe it to everyone to keep on fighting and adhering to the treatment. For example:

> Everyone seems to think that, in the end, I've gotten off rather easy: "You've only got one pill left to take, no more chemotherapy, no more radiotherapy. The worst is behind you." It's all minimized. They consider me to have had only half, or even quarter of a cancer. I have some issues with this. I did have the side-effects of the AHT. I felt impaired in my femininity. The fact that people then minimized it all, that was the most difficult to deal with. Study 17
> " . . . All the effort made by everyone around us to support us. What's taking a pill? We owe them that." Study 21

Women's perception of the treatment does affect their adherence. Patients with negative perception do report their dislike of the treatment and talk about it in a negative way. While patients with positive perception adhere better and experience the treatment with a very positive manner. Change in perception as the treatment continues have been

observed in some cases. The thought of breast cancer continuous lingering because of the long-term treatment is reported by some patients as undesirable. Patients understandably want to forget the bad experience they had to go through and feel that taking hormone therapy is always going to be a reminder of what they had to endure and that they are not cured yet. For example:

> "It's like a trace of what we've experienced, like a passport that you always have on you." Study 21

Women recognize the importance of taking the treatment as prescribed. Therefore, patients try to remember and adapt some techniques to never forget. One of the most mentioned techniques to remember to take the medication daily is to make it a part of the daily routine. Many patients report difficulty remembering when their routine changes either while traveling, on holidays or when their work hours changes. For example:

> "I asked myself what do I do every day of my life? At breakfast, my jar of peanut butter . . . Every morning, it is there." Study 21

Some women report that they have difficulty obtaining the medication due to how expensive it is. Also, some patients report issues with their health insurance as an obstacle to adherence. For example:

> "I have had a hard time on some of my medication. The insurance don't want to pay for it The clinic won't override it and they won't give it to me If I can pay for it I pay for it" Study 8

3.3.2.2 Actions/interactions:

Women tend to need support throughout the long-term treatment phase of the therapy, be it from their healthcare providers, other survivors, family members or close friends. The data supports the idea that patients at this stage are continuously looking for the appropriate support. For example:

> "I really needed understanding, kindness. . .I know that may be it is asking too much but we are not only 'physical' beings..." Study 5

Not getting the information is an obstacle to successful therapy. Patients look to their healthcare providers for information but start to look elsewhere if they are not satisfied with what is provided. While many look for more knowledge about breast cancer, its treatment and the management of side-effects, some reported that by asking questions they were mainly looking for hope and encouragement. For example:

> "Whenever I asked her if she can cure me, I actually just wanted a hope rather than an unreasonable demand" Study 2
> "Even 5-minute conversation (with the doctor) can encourage me A good doctor should give us hope" Study 2

Many women report taking additional medications to manage the side-effects, while others were advised to change their medication-taking habits to better adapt to the treatment. Some report experimenting with alternative medicine to better manage their side-effects. If the side-effects are very severe and patients are unable to live with them or successfully manage them, they could end up switching to another hormone therapy treatment. For example:

> "I was trying to keep it going till I got to the clinic but because I felt I couldn't drive my car I stopped it because it was only about ten days before my clinic appointment But you know I mean I knew that really ten days off it wasn't going to make any difference you know in the long term, so then I got tamoxifen and I'm fine with that" Study 1
> "I go to a homeopathic specialist who gives me trace elements to reduce the side-effects" Study 6

Women report changing their lifestyles to better manage their treatment and its side-effects. For example, patients change jobs, move houses, try to have a healthy life and diet, change training routines, limit social activities, do less housework and have less sexual intercourse. Patients also report the use of coping techniques that ease the

experience. For example, active coping, self-motivation, seeking support, maintaining a positive attitude, meditating, acceptance and using humour to soften the whole experience. For example:

> "We're having to downsize our house so that we can accommodate the fact, because I would rather live in a smaller house costing less money, so that I have the option that if I'm still not well enough I don't have the pressure of having to go back to work" Study 1

3.3.2.3 Consequences:

Despite the many difficulties, many women eventually try their best to adhere with the treatment plan no matter the difficulties. They acknowledge the end point and commit to reaching it to avoid future regrets. On the other hand, some feel that skipping a dose every now and then would not actually harm them. So, some decide to stop the treatment occasionally, especially when the side-effects become more severe. For example:

> "wanting to get to the finish line." Study 11
> "I've got to the stage where sometimes I'll just give it a miss. . .I just get so fed up of taking it, I just want to give myself a break." Study 18

Some women report being surprised by how severe the side-effects are, even believing they would have coped better had they been warned about them in advance. Some report being unable to continue their social activities as before, mainly due to a lack of energy. For example:

> "I started to withdraw from social situations. I didn't trust my body to co-operate. I missed out on quite a few things, because I was too afraid that [due to the diarrhea] I would have to run or, change my clothes or have a shower. And make a mess in public. Emotionally, it was devastating." Study 23

Women might also be taking medications for other conditions or may just be in an older age category. Therefore, they report having difficulty recognizing what is causing their

symptoms, with hormone therapy, other treatments or age getting entangled. For example:

> "It's very hard for me to pinpoint what's causing what because I have all of these different [health conditions]." Study 14

Some women report forgetting if they took the treatment or not, it happens more whenever there is a change to their routine. For example:

> "On Sunday because I'm going to church for communion and I don't have my breakfast or coffee I forget. And I come back after church and I forget." Study 15
> "Everyone acts like the treatment is over. It does not feel like the treatment is over. As long as I have to take this medication, I am not like before." Study 17

3.3.2.4 Mediating factors

The three factors I identified as having an effect on the long-term adherence phase of the treatment are 'the women's ability to adapt to the side-effects of the treatment'; 'support throughout the treatment'; and 'the women's knowledge about the treatment'. These factors either facilitate or constrain the process of adhering to the hormone therapy and the mediating factors or intervening conditions.

The first mediating factor is the women's ability to adapt to the treatment's side-effects. Hormone therapy has many side-effects, which different patients suffer from in different ways. For some the effects are very severe and require medical professional assistance, while for others they are minor and manageable by the patients themselves.

Generally, the female participants in the retrieved studies had tried to adhere to the treatment, believing in its necessity and in the likelihood that it would increase their chances of living longer, healthier lives. However, if the side-effects were severe and patients had a difficult time dealing with and adjusting to them, some were liable to start having second thoughts about the treatment. Even the most optimistic person, if suffering badly from unpleasant side-effects over an extended period and being unable to adapt to

or correctly manage them, is likely to change their perception of the treatment and to question whether the whole process is helping or making them worse.

The second mediating factor is the availability of support throughout the treatment. Women at this stage of the treatment are in need of physical and psychological support, from family, friends and co-workers and of course from professionals. The availability and ease of access to professional support from healthcare providers is necessary, indeed vital, throughout the long duration of the treatment. Some patients reported difficulties of communication between specialists, general practitioners and pharmacists that made finding the help necessary at this stage of the treatment more complicated.

As mentioned previously, the treatment required a good deal of adaptation from the women themselves. The data showed that the women with supportive and understanding families found it easier to adapt and adhere to the treatment. The help and encouragement provided on a daily basis by husbands, mothers and children helped these patient adhere to the treatment, safe in the knowledge that they could turn to their family whenever they faced obstacles or were suffering from the difficulty of their situation. By contrast, many women reported not feeling supported by family members at all, and that they had been negatively affected, and their adherence endangered, as a result.

Many of the women benefitted from support groups, finding great help and comfort in the support of peers treading a similar path to their own. Some placed co-workers and friends in a different category, preferring not to discuss with them the things they might be going through. Some patients felt that friends and co-workers lacked the understanding and even compassion to be of help, preferring them not to meddle in their lives.

The third mediating factor is knowledge about the treatment. Similar to the previous paradigm model, the patient's knowledge is a complicated mediating factor and experience differs from one patient to the next. Many patients reported being surprised by the severity of the treatment and its side-effects, despite being informed by their physician in advance, complaining that the physician had failed to convey quite how gruelling the process could be. These patients believed that, had they been given adequate information beforehand, they would have been more prepared for and better able to

manage their treatment. Others preferred to receive the necessary information as they went and to focus on what they actually needed to do rather than think about what might or might not happen down the line.

The three mediating factors identified in this model, again, act not separately but in concert, interfering with each other throughout the long-term treatment phase (Figure 3-8). The dominant factor was the women's ability to adapt to the side-effects of the treatment. This was found to improve greatly if they were able to draw on support from those around them and understood how to act and manage what they were going through on a daily basis. Hormone therapy is a treatment that is taken for a very long time and ensuring adherence throughout the process requires a lot of work and support.

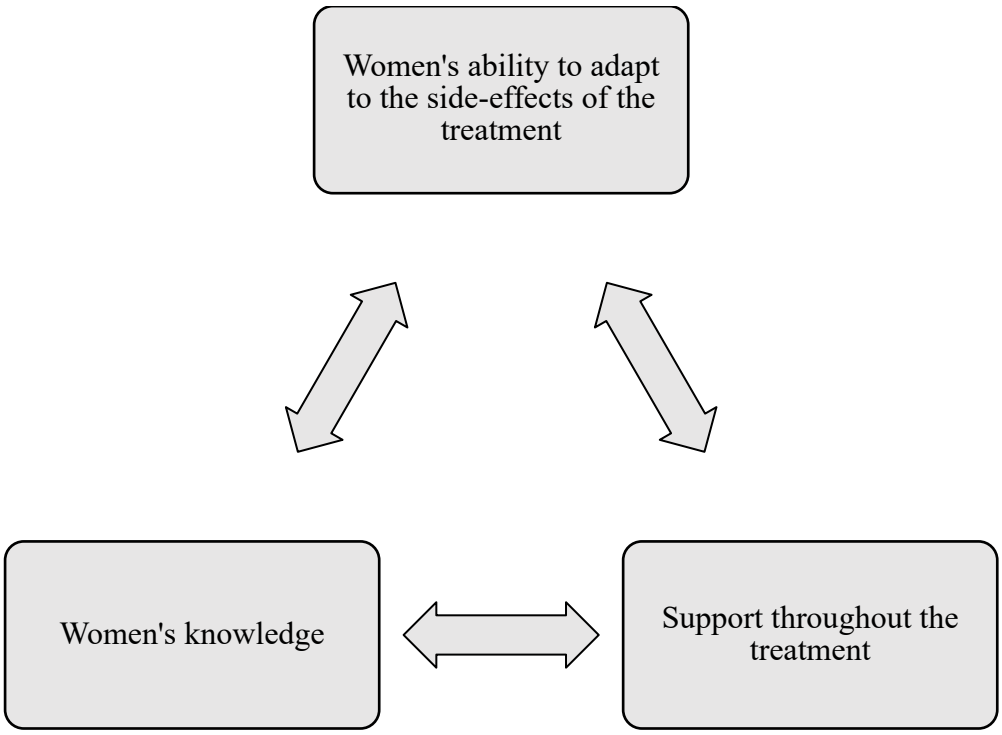


Figure 3-8: The relationship between the three mediating factors identified in the category 'Balancing priorities: adhering to the long-term treatment'.

Context: Adhering to the medication and experiencing the side-effects *After starting the treatment and committing to adhere, women start to experience the medication side-effects, which is unexpected or more severe than they had imagined or expected*				
Quality of life taking precedence over longevity of life	**Causal conditions**	**Actions/interactions**	**Consequences**	**Continuous search for normalcy**
	Severity of the treatment severe side-effects Poor quality of life No trust in the treatment (i.e. negative perceptions of the treatment) Fear of the possible side-effects Being given the choice to stop the treatment by the healthcare provider Faith and religion A sense that existing adherence has already conferred therapeutic benefit Lack of support during the treatment Lack of trust in the healthcare providers and the medical system	Communication with healthcare providers and deciding to stop the treatment Stopping the treatment without communicating with anyone	Stopping the treatment early Accepting that death is not the worst option Better quality of life Regaining control Having a sense of normalcy **Taking a chance: stopping the treatment early**	
Beliefs about the treatment's necessity				

Figure 3-9: The paradigm model for the category 'Taking a chance: stopping the treatment early'

3.3.3 Category 3: Taking a chance: stopping the treatment early

This category describes the stage where patients decide to stop taking the hormone therapy treatment prematurely.

3.3.3.1 Causal conditions:

Women are advised by their healthcare providers to adhere to the hormone treatment for the full duration of the therapy, which could be 5 years or more. However, some patients decide to stop taking the treatment after adhering to it for a shorter duration, which can range from weeks to years in some cases. The most quoted reason for stopping the treatment is severity of the side-effects. For example:

> "You do get to a point where it just isn't worth it to fight it [staying on AET]" Study 3

The severity of the side-effects sometimes affects the women's quality of life. After adhering to the treatment for a while, women can change their priorities. For some, living longer is not their main priority, they prefer to have a more contented life free of side-effects. So they decide to stop the treatment, thus prioritizing quality of life over quantity of years. Some patients would have started the treatment while having doubts about its effect or fearing its side-effects. Their lack of trust in hormone therapy is shown clearly in their quotes. Eventually their negative perception of the treatment leads them to discontinue it whenever they face an obstacle or find someone that encourages them to give it up. For example:

> "I stopped taking it three weeks ago and I feel wonderful. I started feeling better after about a week and every week that's gone past I'm feeling better and better, I feel like me again. I feel great." Study 15
> A friend died from breast cancer, she also took AHT and did not survive anyway". Study 17

Some reported their healthcare provider giving them a clear choice to stop their medication, while others reported they had been ambivalent. Some cited lack of support

during the treatment as a precondition for stopping prematurely, while others reported lack of trust in their healthcare provider and the whole health system as the reason for stopping early. Some felt that they had given the treatment a chance and therefore time to have its effects and that taking it for longer would not benefit them. For example:

> "I have been taking AHT for four years; one year will not make a difference" Study 17

A patient decided to stop the treatment due to her faith and beliefs, that god and prayer is what actually healed her not modern medicine. For example:

> "The reason I'm not taking drugs anymore is my faith. I very firmly believe that God healed me. I prayed. My church prayed for me. I did exactly what God tells us to do in the Bible and that is to go to Him and ask Him and give Him all the credit for it first, and He did heal me" Study 4

3.3.3.2 Actions/interactions:

In some cases, women and their healthcare provider might reach a decision together to stop the treatment, however, the patient might decide to stop the treatment without discussing their decision with anyone. For example:

> "[My oncologist] pulled out my chart … all my history, and we sat down. She said, "You have a very low risk of the disease coming back, and you are very sensitive to drugs. [Given the odds], it would be OK if you went off the drug." She said, "I have no problem if you make that decision." So, that's what I did." Study 20
>
> "I took myself off the medicine. I went to my primary care physician and told him what I had done. He almost had a heart attack … and I said, "I've had tamoxifen, and I've had breast cancer. I would rather have breast cancer." Study 20

3.3.3.3 Consequences:

For a number of reasons then women might decide to stop taking the treatment prematurely. Having the choice, the patients felt that taking the treatment is not necessary, so, they did not see the necessity of suffering through the treatment and its side-effects and eventually they decided to stop. For some living with the treatment long enough and suffering from it led them to believe that living longer is not what only matters anymore. Sometimes quality of the woman remaining years is more important than its quantity. Some women felt that breast cancer and death are not worse than continuing the treatment. For example:

> "I chose a lesser time left. I said at my age, does it matter if the cancer comes back one way or another but if I have these few years of, I don't go gallivanting or that, I like my home and I like being involved in the community, going to the club and that. Coming off the tablet has given me back that quality of life". Study 15

Many women reported feeling much better after stopping the treatment, feeling happier, more energetic and like their old selves. They felt that their quality of life had improved greatly and that they had finally found a sense of normalcy, that they had lost since being diagnosed with breast cancer. For example:

> "I stopped taking it three weeks ago and I feel wonderful. I started feeling better after about a week and every week that's gone past I'm feeling better and better, I feel like me again. I feel great." Study 15

3.3.3.4 Mediating factors

I was able to identify various factors as having an effect on the women in the study stopping hormone therapy prematurely. These factors affected the length of time the women might adhere to the treatment before deciding to stop it. The mediating factors identified in this model are 'quality of life taking precedence over longevity of life'; 'beliefs about the treatment's necessity'; and 'continuous search of normalcy'.

The first mediating factor is quality of life taking precedence over longevity of life. As women go through the journey of hormone therapy and begin to suffer from the treatment, with its severe side-effects and other life-changing difficulties, their perception of the treatment might start to change, and they might decide that taking the treatment for a longer duration is not worth it. Generally, from the previous models and the available data, it is clear that patients, naturally, want to live as long as possible. However, after enduring the treatment for a certain period their views might change, the duration differing from one patient to the next. Patients might then start hankering after a happier, "normal" life, even if this means a shorter one, and thus start to prioritize happiness and normalcy over longevity. Some patients at this stage prioritize quality of life over everything else and come to accept that cancer recurrence, even death, is not their worst option.

The second mediating factor is women's beliefs about the treatment's necessity. Women who believed in the necessity of the treatment reported trying to adhere to their physician's advice. Those who then decided to cease medication did not do so by themselves but were given the choice to stop taking it by their healthcare provider. However, there was another group of patients who started the treatment with a negative perception, questioning its necessity and being open to arguments supporting their scepticism. Naturally, suffering unpleasant side-effects from the treatment only confirmed these patients in their view, making them less likely than before to continue the treatment.

The third mediating factor is continuous search of normalcy. Hormone therapy is associated with many side-effects that require adaptation and lifestyle modification to accommodate them. The women on the treatment who adapted and managed their treatment well were usually about to stick to the treatment plan and continue the therapy for its full duration. This is extremely difficult to do, however, and many patients reported their inability to adapt their life to the requirement of the treatment. They found the treatment prevented them from maintaining normal lives, which caused some of them to decide against continuing the treatment and instead attempt to regain normalcy.

The three mediating factors identified above act not separately but together, interfering with each other throughout this phase of the treatment (Figure 3-10). The most dominant

factor is quality of life taking precedence over longevity of life. The severity of the side-effects and the amount of changes necessary to accommodate to the treatment were deemed by some women to be too great a price to pay even for the possibility of prolonging life, eventually leading them to give up on the treatment.

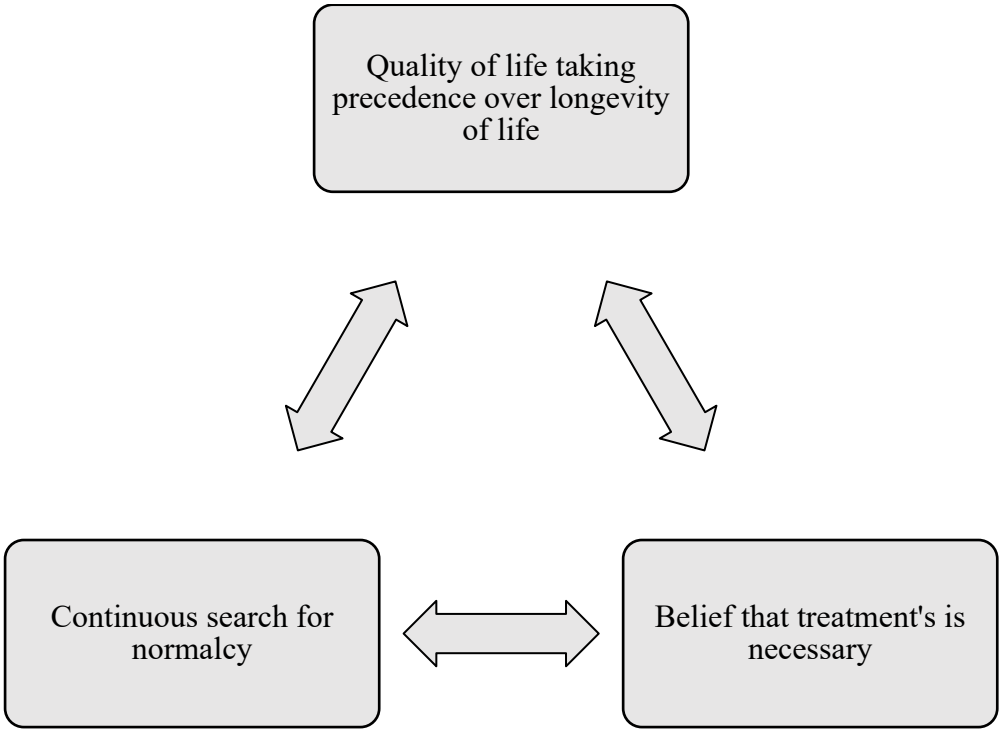


Figure 3-10: The relationship between the three mediating factors identified in the category 'Taking a chance: stopping the treatment early'.

3.3.4 Core category "Hobson's choice or a horned dilemma?":

To understand the core category, one must define what these two phrases mean. *Hobson's choice* is a free choice where only one thing is offered without any alternatives. The phrase originated in the 16th century with Thomas Hobson, who was a stable owner in Cambridge, England. Thomas offered customers the choice to either take the horse in the stall nearest to the stable door or take none at all (Freeman, 2002). On the other hand, a *horned dilemma* is about being faced with a decision between two unfavourable and difficult options. Here, no matter what you try to avoid you end-up being impaled by your own decision (Ayto, 2010).

At the beginning during the prescription phase, patients are asked to take hormone therapy for a certain duration of time. Despite this being consensual, some women feel that they do not have a real choice in the matter, this could be attributed to their fear of recurrence, and beliefs about the necessity of the treatment and potential harm if they decide not to take the medication. For them the choice is a Hobson's choice due to the lack of alternatives. And it continues being so until they reach the end of the treatment.

On the other hand, some think of adhering to the treatment as a horned dilemma. Patients who fear the treatment, fear its potential side-effects or others who have taken the treatment for a little while and started to experience severe side-effects, feel like they are stuck between these two bad options. They constantly question whether they should continue the treatment and power through the side-effects or stop and take their chances with cancer potentially returning. Fear of cancer recurrence and the fear of having no one but themselves to blame if cancer returns is one side of the argument versus fear of the treatment itself and the side-effects associated with it on the other side. It is a very hard decision to make due to both options being associated with bad outcomes. Thus, this situation for the women creates a horned dilemma which some face continually throughout the treatment and metaphorically speaking, it seems that no matter which horn they escape they still get impaled by the other.

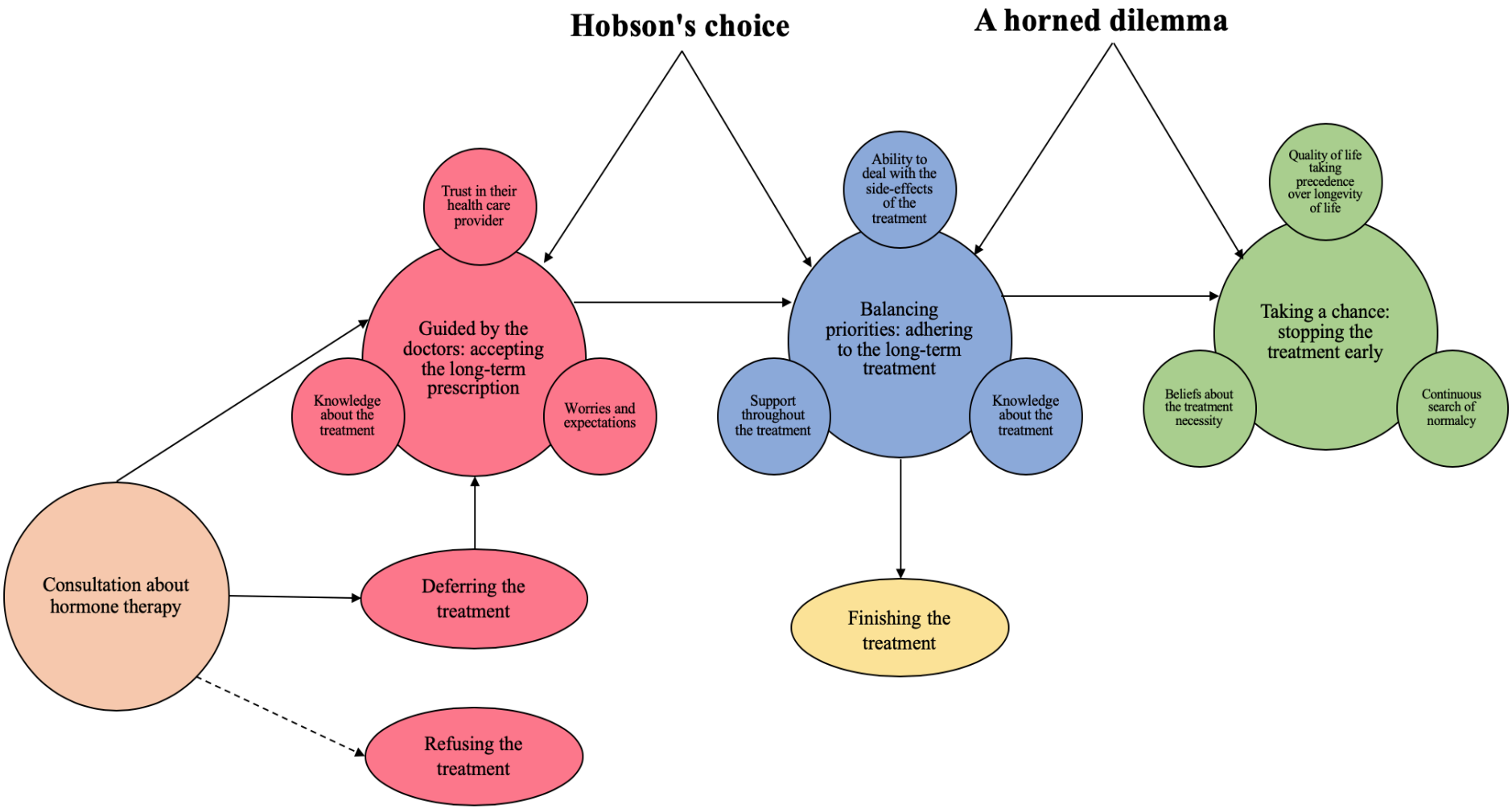


Figure 3-11: Core Category "Hobson's choice or a horned dilemma?

3.4 Discussion:

The findings of this study suggest that women on breast cancer hormonal treatment are divided, broadly speaking, into three groups. The first is where women who think of the treatment as a Hobson's choice. Here, women are more likely to adhere to the treatment due to their beliefs about its necessity and are more tolerant to the side-effects of the treatment too. The second is where women on a hormonal treatment think of it as a horned dilemma; these women if faced with a difficulty are more incline to stop the treatment, they are less tolerant to side-effects and their beliefs about the treatment necessity are not as strong as the first group. The third group are women who start the treatment thinking of it as a Hobson's choice, however, when adherence becomes difficult, their views start to change, and the decision on whether to continue on the treatment or not becomes a horned dilemma. The findings of this study could help healthcare providers identify how women view their medication so as to detect any adherence issues that could arise in the future, in advance. Thus, deal with it and help patients navigate their experience and continue with the treatment in light of their beliefs.

Previous studies have documented the extent of non-adherence to hormone therapy in breast cancer survivorship despite the documented risks (Owusu et al., 2008; Partridge et al., 2003; Atkins and Fallowfield, 2006; Partridge et al., 2008; Güth et al., 2008). Much of that literature considers medication adherence from a biomedical standpoint, seeing non-adherence as a 'challenge' that needs to be tackled, for example with the use of an 'intervention' (Donyai, 2019). In contrast, this chapter focussed on collating the experiences of women prescribed hormone therapy to help explain the phenomenon using, as much as possible, an 'insider' perspective. The rate of publication of qualitative studies (which largely look for the insider perspective) in this area has increased sharply, with 17 studies of the 24 included in this review having been published in the last 5 years. However, to my knowledge my study is the first to synthesise the qualitative literature and develop a theoretical understanding of women's experiences with long-term hormone therapy for breast cancer using grounded theory. My theory helps explain why, having committed to taking tamoxifen or an aromatase inhibitor, adherence decreases over time, and importantly, it shows the decision to cease treatment early as an active choice that is

made with a credible rationale. Health professionals can use this grounded theory to support women via client-centred approaches.

My study also illustrates the importance of knowledge to women at the different stages of the treatment. It suggests that empowering women with knowledge about the treatment and setting appropriate expectations beforehand, especially about the side-effects, could help improve their experience of taking hormone therapy. An educational tool for use throughout the treatment could help probe for and address a range of issues that might not otherwise be addressed. Specifically, knowledge about the treatment itself, why it is needed, and the range of side-effects that might be encountered could be discussed and explored. The shift in responsibility as women begin taking hormone therapy and the dwindling professional support available to them has been recognised elsewhere (Kahn et al., 2007) and is worth highlighting. This is especially important when access to specialists and oncologists is withdrawn and other healthcare professionals are seen by the women either to lack expertise or the interest to provide support. A learning tool to support the knowledge of non-specialist health professionals might also prove helpful to women.

The current study is in coherence with the Necessity-Concern Framework (Horne and Weinman, 1999), which relates specifically to medication adherence and proposes that this behaviour is linked to the balance of treatment concerns against beliefs about treatment necessity. This is in essence what the women on hormonal treatment do according to my findings. Women who think of adhering to hormone therapy as a Hobson's choice, believe that the treatment is necessary and that adhering to it will prevent cancer recurrence, no matter the severity of the side-effects. They are unlikely to entertain the idea of stopping the treatment and try instead to take their medication exactly as prescribed on a daily basis. On the other hand, some with weaker beliefs about the treatment necessity who experience the side-effects, start accumulating concerns about the side-effects, leaving them with the difficulty of the horned dilemma. This congruence between the core category and the Necessity-Concern Framework provides an additional layer of credibility to the study. However, the findings of this study are particularly useful as, unlike the Necessity-Concern Framework, the specific beliefs and experience of women on hormone therapy is detailed and presented as a complex and dynamic model.

A limitation of the study was my lack of access to the original interview transcripts with the analysis built on the quotes that were extracted by the original authors to include in their papers, and their respective interpretations. Nonetheless, the model was based on 801 quotes, extracted from 24 studies to reflect the experiences of 610 survivors of breast cancer. I believe that this provided a sufficient basis to develop a theoretical understanding within the context of a qualitative meta-synthesis. The interview study detailed in Chapter 5 was conducted based on the categories described in this Chapter, allowing further examination of the theory for currency in a UK setting. The current model arguably provides a basis for informing survivors of breast cancer and health professionals too about the challenges of medication-taking before and during the treatment process. Therefore, the next chapter details the development of pictograms as a means of simplifying and communicating these ideas.

Chapter 4: Pictograms: development of the grounded theory models for health communication

4.1 Introduction

Communication between healthcare providers and patients has always been problematic (Clawson et al., 2012). Healthcare professionals, despite their attempts to simplify information, still tend to use medical terms, whether because this is the vocabulary that comes easiest to them or for lack of alternatives. Also, they often provide more information than patients can absorb or retain (Houts et al., 2006). One way to transmit information and facilitate understanding is by using pictograms and this applies in the healthcare field as much as anywhere. Multiple studies have looked at the effectiveness of using pictograms in health care to illustrate the use of medical devices, drug indications, dosing schedules, side-effects and special instructions for the administration of medication, founding positive results (Kripalani et al., 2007; Montagne, 2013). These ideas also relate to health literacy.

Health literacy is defined as "the degree to which individuals have the capacity to obtain, process and understand basic information and services needed to make appropriate decisions regarding their health" (Barros et al., 2014). The use of pictograms allows people with different health literacy levels to better understand and recall information. What is more, combining the use of text and pictures has been shown to affect health communication positively in multiple studies (Barros et al., 2014; Kripalani et al., 2007).

In Chapter 3, I used grounded theory synthesis to appraise, summarize and synthesize data from existing qualitative studies. I was able to develop an in-depth explanatory model of breast cancer survivors' hormonal medication experiences. The study resulted in the development of three main categories: 1) 'Guided by the doctors: accepting the long-term prescription'; 2) 'Balancing priorities: adhering to the long-term treatment'; 3) 'Taking a chance: stopping the treatment early'. The core category explored whether and in what way the patient's decision to take the medication was a case of a "Hobson's choice or a horned dilemma?". Hobson's choice describes a situation where only one really viable option is offered, and encapsulates the decision faced by many patients at

the start of the treatment. A horned dilemma, on the other hand, is facing two equally bad options, in this case having to tolerate the unpleasant side-effects of medication or stopping the treatment and risk losing the prophylactic cover afforded by the medicine.

The analysis also highlighted a need for better patient-professional communication. This need might be met with an educational tool that can inform breast cancer survivors and healthcare providers alike about the experiences of other women on hormone therapy. Such a tool might then inform women's decisions on whether to accept medication for the long-term management of their condition, and also help them manage the different stages by mapping what might lie ahead. The three paradigm models are very comprehensive due to the fact they were developed based on the views and experiences of 610 women with a breast cancer diagnosis in 24 different studies, thus providing a more general and inclusive understanding of the phenomenon than any other stand-alone study published before. Therefore, the models have the potential to inform the development of an educational tool that explains what women go through at the beginning of their treatment or on a day-to-day basis during it. The length and complexity of the models, however, presented a problem. I therefore took the decision to develop the three models into three sets of pictograms to make them easier to understand by anyone, no matter their level of education. The aim of this part of the study was to develop and design a set of pictograms that explain breast cancer survivors' experiences while taking a hormonal treatment for the long-term management of breast cancer, based on the paradigm models presented in the previous chapter (Figure 3-5, Figure 3-7 and Figure 3-9).

4.2 Aim

To develop and design a set of pictograms that explains women's experiences while taking a hormonal treatment for the long-term management of breast cancer, based on the paradigm grounded theory models presented in the meta-synthesis study.

4.3 Methods

I aimed to use the three models representing the main categories from the previous chapter, developing them into a set of pictograms for easier communication. To design

the pictograms I followed the recommendations by Rohret and Ferguson, (1990), Dowse and Ehlers (1998) and Houts et al. (2006). The recommendations are summarised as follows:

1. Healthcare educators should look to include pictures in their health communications.
2. Use simple and easy to interpret pictures.
3. Use simple and easy to understand language with the pictures.
4. Guide how the pictures are perceived and interpreted by viewers.
5. Be sensitive with the creation of the pictures to the culture and feelings of the intended audience.
6. Involve healthcare professionals in the creation of the pictures.
7. Evaluate the pictures and their effect.

All these recommendations were taken into consideration in the creation of the pictograms in my study. The design of the pictograms was first developed and agreed on by myself and my primary supervisor. The contents were then validated for accuracy and meaning by a panel of healthcare professionals and researchers (n=10). After applying the required changes and producing the final models, the content was examined by an additional group of experts (breast cancer survivors) (n=14).

4.3.1 Drafting the initial idea of the pictograms

Based on the grounded theory models produced in the previous chapter, the first stage of pictogram development was performed by me in consultation with my primary supervisor and consisted of two steps. The first was identifying the possible drawings of each category in the models that best reflected the category. The second was choosing the text to go with each category, making sure it clearly defined it. After multiple meetings to determine the final draft, I worked with an external graphic designer (Omar AlOmeir, a personal contact) who helped by producing the actual drawings. I designed each pictogram to make sure all information relevant to the category was included and clearly defined, while making it as simple and as easy to understand as possible.

4.3.2 Drafting the initial pictograms

I worked with Omar who helped make any amendments to the drawings as per my requirements. The first and second drafts were amended and an improved third design was produced and agreed with my supervisor on for the second stage of validation.

4.3.3 The validation questionnaire (Content Validity Index (CVI; I-CVI))

Next, I developed a questionnaire for an independent study panel to examine each category of the original model against its designed pictogram and thus provide me with feedback using content validity methodology. I formed my panel by seeking volunteers during one of our PhD student monthly meetings, where 8 fellow pharmacists and researchers agreed to join my panel. The remaining 2 recruits were doctors I knew personally from my studies in Saudi Arabia. The number of panel members (n=10) was based on criteria developed by Lynn, who advised that a panel should consist of a minimum of three and a maximum of ten people, deeming anything above ten to be unnecessary (Lynn, 1986). I included healthcare providers at this stage of the process in line with the recommendations of Rohret and Ferguson (1990), Dowse and Ehlers (1998), Houts et al. (2006), and Barros et al. (2014).

The chosen panel was asked to answer a questionnaire consisting of 76 pictograms, taking into account the categories they were designed to represent. For each category they were asked, “Does the sentence in the first column [description of the category in the grounded theory model] represent the content in the second column [the newly designed pictogram]?” The panel members were given the option to (1) “strongly agree”, (2) “agree”, (3) “disagree” or (4) “strongly disagree” with the statement; see the example below (Figure 4-1) (The full questionnaire is shown in Appendix 4.). This four-point scaling system is frequently drawn upon in the literature and was recommended by Lynn (1986), Davis (1992), and Waltz and Bausell (1981) among others.

Description	Pictogram	Representation		
Transitioning into a new stage of breast cancer treatment		**1**	**Strongly agree**	√
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	

Figure 4-1: An example of an answered question in relation to the general question "Does the sentence in the first column (Description) represent the content in the second column (Pictogram).

The Content Validity Index (CVI; I-CVI) helps in measuring the percentage a tool represents a construct (e.g. pictogram representing the description) based on the recruits' assessments. Thus, I-CVI allows the researcher to improve the tool when the result deems it to be necessary. Based on Lynn's criteria I calculated I-CVI for every pictogram by dividing the number of panel members giving a rating of 1 or 2 by the total number of the panel. For example, if a pictogram was rated "strongly agree" or "agree" by 9 panel members out of 10, it would have a I-CVI of 0.90. This dichotomization of the scale to "agree" or "disagree" is a step recommended in the literature (Lynn, 1986; Polit and Beck, 2006; Ibrahim et al., 2018). Based on this recommendation, any pictogram with an I-CVI less than 0.8 was deemed in need of modification (Lynn, 1986; Polit and Beck, 2006). In addition, the content validity scale-level content validity index (S-CVI) was calculated for the three models separately and as a collection by calculating the average of the I-CVI for all items in the specific model, while the overall S-CVI was calculated using the same method of calculation. This method is referred to in the literature as the "averaging calculation method" and is usually acceptable with a S-CVI > 80% (Polit and Beck, 2006).

4.3.4 A further meeting to complete the pictogram

After calculating the results of the questionnaire I organized a meeting with my research panel members who had answered the questionnaire (n=10), in order to discuss the pictograms with a CVI < 0.8. I conducted the meetings with the two externally based panel members (from Saudi Arabia) using email/Skype. Agreement was reached between everyone involved about the changes necessary to improve the pictogram, whereupon the external designer was contacted once again to implement the agreed modifications.

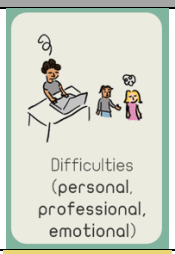
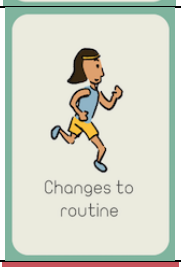
4.3.5 Qualitative interviews with experts (breast cancer survivors)

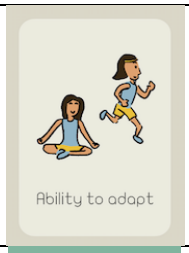
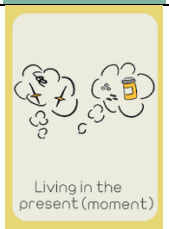
The final stage of the validation process took the form of a series of qualitative interviews held with a panel of breast cancer survivors (n=14). The interviews were semi-structured and consisted of a discussion about the three models to ensure their clarity, simplicity and accuracy in depicting the condition each was intended to represent. I completed each interview in a face-to-face meeting. Further detail about the recruitment and conduct of these interviews is detailed in Chapter 5. This ordering is because, the pictograms were initially developed following the meta-synthesis study (Chapter 3), then discussed during the interviews with my breast cancer survivors (Chapter 5), with their initial development detailed here (Chapter 4).

4.4 Results

The original pictogram was examined by a panel of ten people, as described above, to check it for relevance, clarity and simplicity. The results of the questionnaire showed that of the 76 pictograms, 13 had an I-CVI < 0.8 and so were deemed to need modification (see Table 4-1).

Table 4-1: The categories and pictograms that required modification and their I-CVI.

No.	Description	Pictogram	I-CVI
1.	**Experiencing difficulties during the initial stage of the treatment (*personal level, professional level or emotional level*)**		0.5
2.	**Being wrongly informed about the medication (*side-effects, mechanism of action, efficacy and safety*)**		0.7
3.	**Trust and belief in the treatment and its necessity**		0.7
4.	**Receiving the correct information about the treatment and side-effects in advance**		0.6
5.	**Changes in the patient's usual routine**		0.5
6.	**Trying to manage the side-effects**		0.6

7.	**Lifestyle modifications to adapt to the treatment and its side-effects: Quitting work due to lack of energy, moving to a smaller house, routine changes (sport, social activities, travelling, housework and sexual intercourse), living healthier (diet and exercise)**		0.7
8.	**Ability to adapt to the side-effects of the treatment**		0.7
9.	**No trust in the treatment (negative perception of the treatment)**		0.6
10	**Fear from the possible side-effects**		0.7
11	**Lack of physical and emotional support during the treatment**		0.6
12	**Lack of trust in the healthcare providers and the medical system**		0.6
13	**Patient accepting that death is not the worst option**		0.5

In a meeting that took place after the results of the questionnaires had been calculated, my panel agreed on the changes necessary to improve the pictograms' representation of the descriptive text. The panel agreed to keep the text in the pictograms as it was while applying the following changes to the drawings seen in the above table (Table 4-1). The agreed changes are shown in Table 4-2 below:

Table 4-2: The modifications agreed on by panel members and authors to improve the pictograms' representation of the description.

No.	Description	Changes required
1.	**Experiencing difficulties during the initial stage of the treatment (*personal level, professional level or emotional level*)**	A drawing of someone pulling their hair
2.	**Being wrongly informed about the medication (*side-effects, mechanism of action, efficacy and safety*)**	Add a patient face
3.	**Trust and belief in the treatment and its necessity**	Thumb up to a pill or a tablet instead of shaking hands
4.	**Receiving the correct information about the treatment and side-effects in advance**	A drawing of a book and a happy face
5.	**Changes in the patient's usual routine**	A drawing of someone going on a holiday
6.	**Trying to manage the side-effects**	A drawing of someone suffering from hot flushes (face sweating)
7.	**Lifestyle modifications to adapt to the treatment and its side-effects: Quitting work due to lack of energy, moving to a smaller house, routine changes (sport, social activities, travelling, housework and sexual intercourse), living healthier (diet and exercise)**	Add a drawing of someone running and doing yoga
8.	**Ability to adapt to the side-effects of the treatment**	A drawing of a suffering face and a happy face
9.	**No trust in the treatment (negative perception of the treatment)**	Instead of a hospital, a drawing of pills, tablets or both
10.	**Fear from the possible side-effects**	A drawing of a face of someone thinking of bad things
11.	**Lack of physical and emotional support during the treatment**	A drawing of a crowd of people with the main person isolated
12.	**Lack of trust in the healthcare providers and the medical system**	Add a doctor next to the hospital
13.	**Patient accepting that death is not the worst option**	A drawing of someone dancing

The S-CVI was then calculated for each model separately, using the averaging calculation method. The results are seen in Table 4-3 below.

Table 4-3: The S-CVI for model 1, model 2, model 3 and the overall S-CVI of all three models combined.

Section measured	Model 1 S-CVI	Model 2 S-CVI	Model 3 S-CVI	The overall S-CVI
S-CVI	86.5%	87%	80%	85.1%

A range of comments were also made by the breast cancer survivors (experts) in relation to the quality and representation of the pictograms, as can be seen from their answers to the following questions: "Do you find yourself in the pictogram?", "Would you like to add anything to it?" and "Do you think these pictograms are useful? How? And to whom?" See Table 4-4 below.

The final set of models, as agreed on by me, my supervisor, panel members and experts (breast cancer survivors), are shown below (Figure 4-2 for the first model 'Guided by the doctors: accepting the long-term prescription', Figure 4-3 for the second model 'Balancing priorities: adhering to the long-term treatment' and Figure 4-4 for the third and final model 'Taking a chance: stopping the treatment early').

Table 4-4: Experts' comments in regard to the models and pictogram representation of their own experiences.

Do you find yourself in the pictogram?
"Yeah, but yes I can identify with many of those things. Not all but yeah, to some degree most of them, yeah." Interview 1 "I do, yeah I can relate to a lot of that without even thinking that I probably was in that little cycle that you've just done that…" Interview 3 "Yeah. That is me to a tee. That's quite scary. Yeah, that is quite scary." Interview 6 "Yeah definitely a part." Interview 7 "Yes I do. In almost all of the boxes." Interview 8 "Yes, I think so. I think there and there probably and accepting and then trying to do some of those." Interview 9 "I do, yes. Yes. Most definitely." Interview 11 "I think I recognize myself in quite a lot of that as well." Interview 12 "Yes I do. I recognize all of that" Interview 14
Would you like to add anything to the pictogram?
"No, I think that sums it up very well actually and it's helped me to tell you more about my treatment cycle." Interview 2 "No, that's it, yeah." Interview 5 "No. I think that is absolutely true in every one of those, yeah, definitely." Interview 6 "No, I don't think so. I think that is spot on." Interview 6 "No I think you have included pretty much everything to be honest." Interview 8 "No, I think you have captured everything to be honest." Interview 8 "Wow. Well done, that's perfect actually, that's captured everything to be honest. Yeah well done." Interview 8 "No, that's very thought-provoking." Interview 9 "Yeah, no I think it yeah it does cover, every little one of them I can see myself in, yeah. So yeah, that's good. It seems to have covered, I can't think of anything that you haven't put on there, so…" Interview 10 "No. I think that's, that's probably right." Interview 11 "I think it covers all the things that are if you like the negatives that people come across and that would influence them on continuing to take the treatment. Yes, very much so." Interview 13 "No, I think that's really, really good, I think that will be really helpful." Interview 14

Do you think these pictograms are useful? How? And to whom?
“Yes, it does. Yes, oh right that’s a useful diagram.” Interview 2 “Yeah let’s just hope that something comes of it, that it helps to, yeah.” Interview 10 “And you go, yeah, yeah, it is, in fact it’s normal because that’s what I felt. So it then validates the fact that I was feeling it must be OK because someone else has felt it so I wasn’t going mad, if you know what I mean.” Interview 11 “I think it would actually because, you know, for example, the consequences of the cancer feeling lingers on. That will, if I knew that, that, that’s, that studies report that, then I wouldn’t have spent so many hours thinking I was actually going mad. And it was only when my, another one of the ladies mentioned it about, you know, I can’t stop thinking I’m going to die, that I was able to say, oh I felt like that. So, it normalized it for both of us.” Interview 11 “Yes, yeah, because it’s setting out all of the possibilities of what’s likely to happen and you can think, well, some will and some, you know, and as long as you’re told, well, some will and some won’t, you know.” Interview 11 “Wow. That is really good. That does encapsulate exactly how it feels, in a way. Gosh.” Interview 11 “Yeah, no worries. I mean, I’m hoping your thesis or dissertation or whatever it calls, whatever comes of all of your studying will actually make it. I certainly think if I’d have had some of these pictures to look at before, you know, sort of, five or six years ago, it would have helped me, not, I mean, I don’t suppose for a minute it would stop me thinking I was going mad but it would help thinking, well, hang on a minute, that is normal.” Interview 11 “I think this is fantastic. Absolutely.” Interview 11 “Yeah, that is really good because there are very many GPs who are, I mean it’s something like one in eight women get breast cancer and it’s only about 10% don’t take hormonal therapy so actually this would be very helpful particularly as it is something quite new for them to have to deal with.” Interview 13 “I think that’s really great for the GP, yeah. Thank you. Or for anybody that’s involved in prescribing or giving out information.” Interview 13 “Oh, very much so, yes. I do think that because what it does is it puts it in their mind that they’re not on their own as it were. So, yeah, so from that point of view it makes it easier to understand that there are, while it is a very positive thing for your general health at the time that it’s not straightforward and there could be problems but which can be managed.” Interview 13

“Yes I do. I do actually, I think it gives a framework and stages and well some of it’s stages isn't it? I think it would help the healthcare provider as well, it gives a focus that isn't lengthy written information. I think it is very good and I like the pictures and everything.” Interview 14

“I think that they ought to take, this is such strong medication that actually they ought to approach it in that way and review it using the kind of framework you’ve got here.” Interview 14

“It would help me if I was say a breast care nurse or something like that I would find this very, very helpful to go through. I would find it also if I was a, I'm doing this from a nursing point of view, because that’s my background, but I would actually look at the education needs of staff if I was a manager in terms of their preparation, in-house also if we send staff on courses does it cover this kind of thing, how do they demonstrate that they're competent in all of this. I would, that’s what I would be looking for. And I think doctors would benefit from, at least following, I think some of them do but it’s going in more depth. Or knowing, having somebody in the team who can do this. They don’t all have to be expert at it, but somebody who can. I think it will be very, very good.” Interview 14

“Yes and I like the way you’ve done it. I like the way, I like all of your, the pictures you’ve got as well.” Interview 14

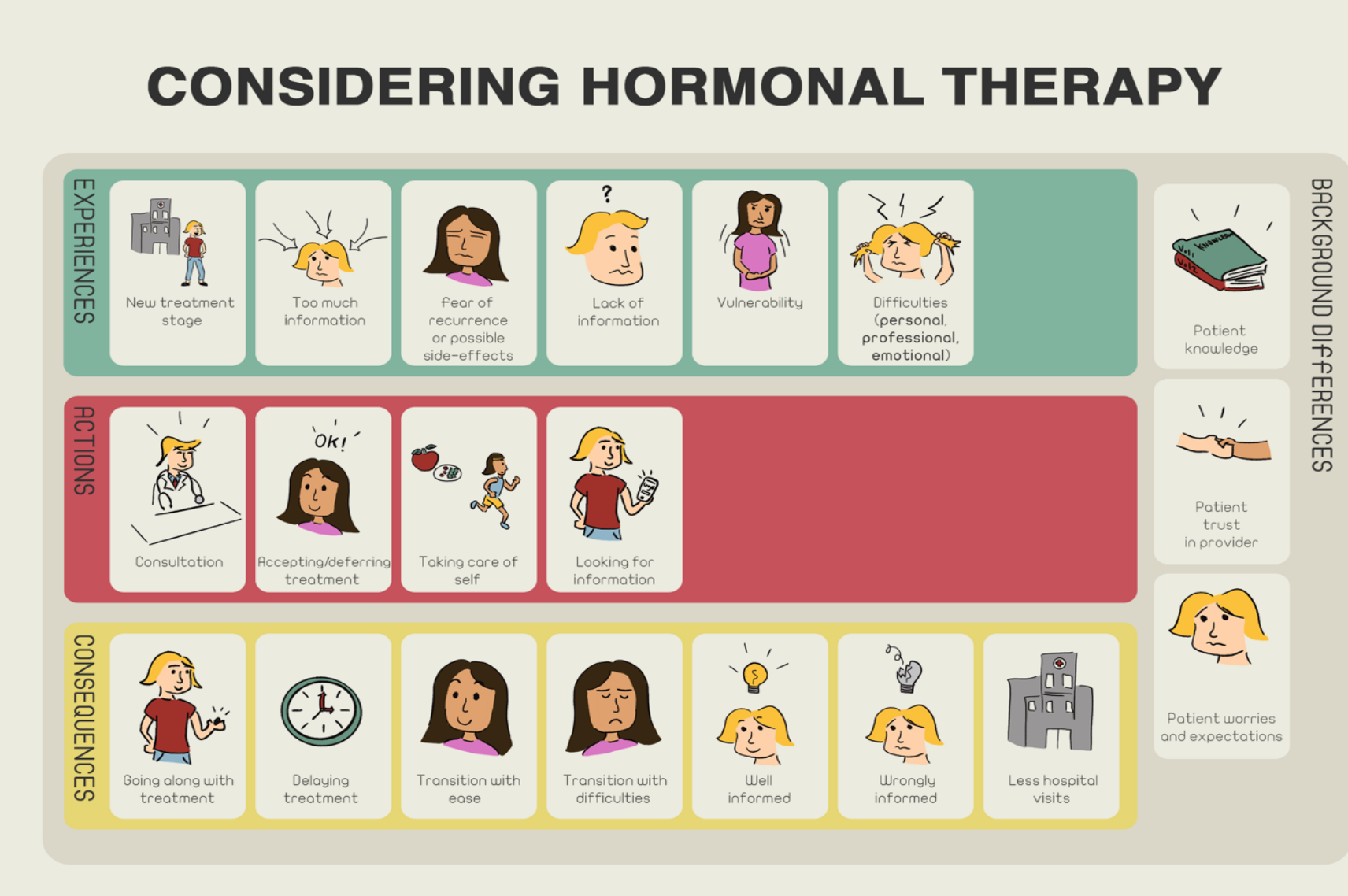


Figure 4-2: The paradigm model for the category 'Guided by the doctors: accepting the long-term prescription'.

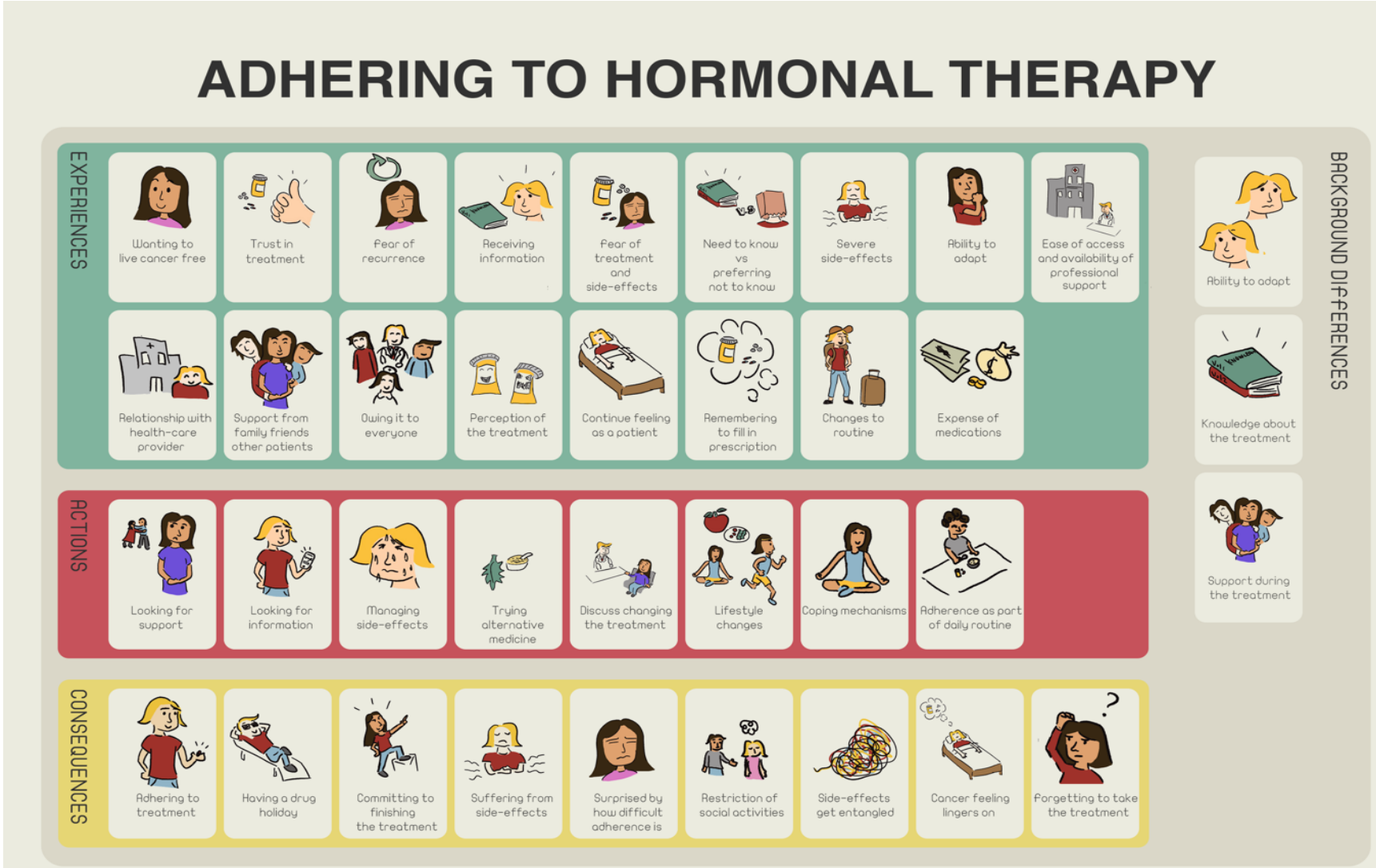


Figure 4-3: The paradigm model for the category 'Balancing priorities: adhering to the long-term treatment'.

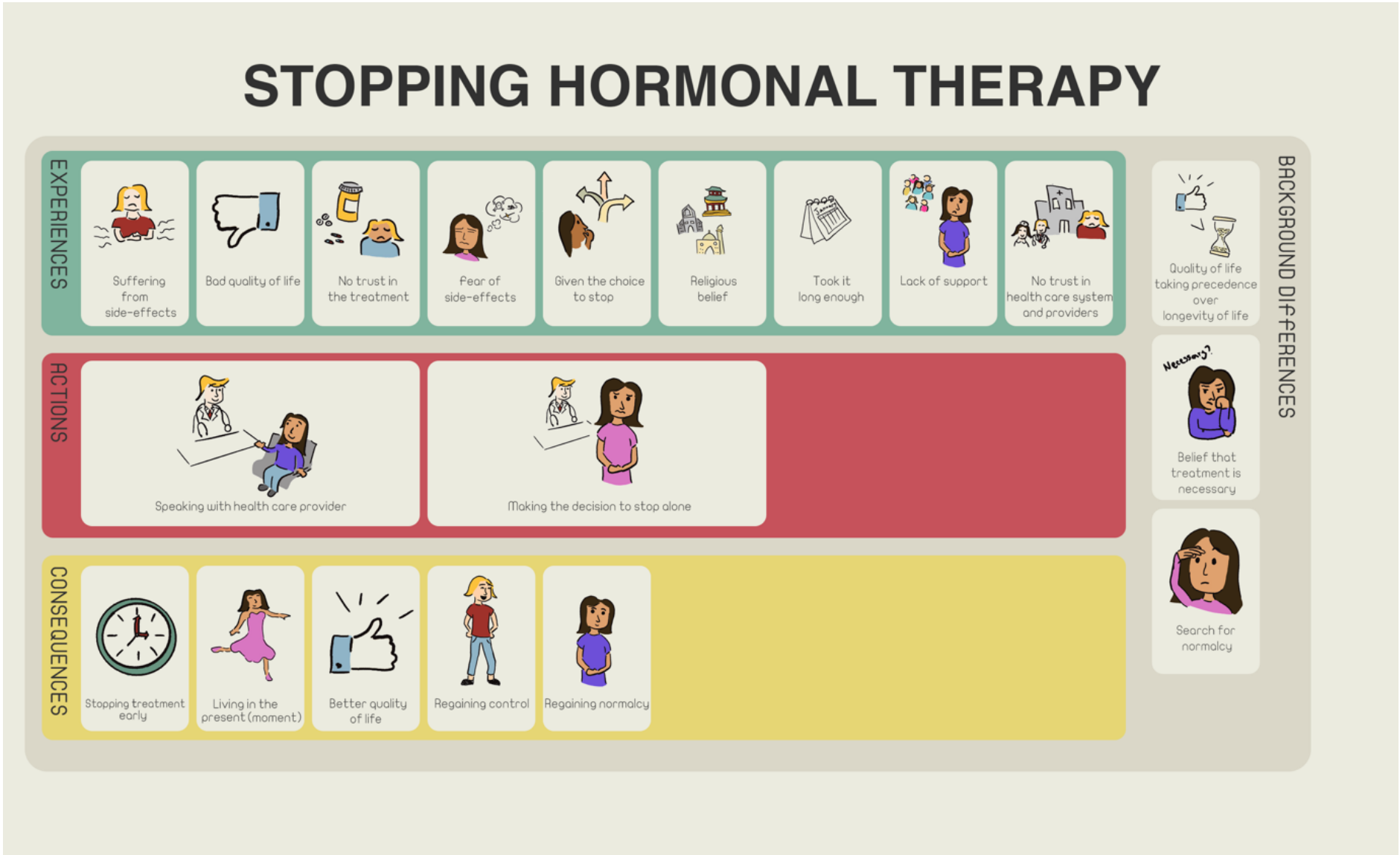


Figure 4-4: The paradigm model for the category 'Taking a chance: stopping the treatment early'.

4.5 Discussion

The development of the pictograms took multiple steps and a lot of time to make sure the pictures and accompanying texts were clear, valid and actually conveyed the category they represented. The inclusion of an external graphic designer in the development of the pictograms, as recommended by Barros et al. (2014), enhanced the drawing and colouring and helped capture the emotion and facial expressions appropriate to each picture. Subsequently, with the help of healthcare professionals who were also fellow researchers, I was able to check the representational effectiveness of each pictogram. The pictograms deemed in need of change by my panel were then altered to meet the panel's recommendations. The inclusion of healthcare providers at this stage of the process is in line with the recommendations of Rohret and Ferguson (1990), Dowse and Ehlers (1998), Houts et al. (2006), and Barros et al. (2014), and proved helpful in providing a different point of view and highlighting small things that I and my primary supervisor were unable to see, due to our familiarity with the categories.

In the next step, the final set of pictograms were shared with and explained to breast cancer survivors to seek their opinions, following the recommendations by Rohret and Ferguson (1990), Dowse and Ehlers (1998), and Houts et al. (2006). This step provided me with a first practical response to the pictograms by breast cancer survivors whose experiences these were aiming to capture. The involvement of end users in an informative and consultative role is not new. A systematic review published by Van Beusekom et al. (2018) discussed the idea and the benefits of their inclusion. However, although that study concluded that including experts would increase the likelihood of the resulting pictograms being understood and well received, the nature of their involvement was not clearly stated. Most studies included in their review had an incomplete description of the process.

In my study, women survivors of breast cancer as experts were recruited for qualitative interviews for three reasons: to validate the already established pictograms, to measure their understanding of the pictograms, and to listen to their recommendations. Their responses, as demonstrated above, were extremely positive. All participants were able to 'find themselves in the pictograms', stating that they captured their own story fully and were easy to comprehend. When asked about how beneficial they found these pictograms

to be, multiple participants said they were relieved by how such a pictogram normalized their own experience. The pictograms also worked as memory triggers, helping some participants remember parts of their experience they had forgotten or identify with other aspects that they did not know were common among those experiencing a similar medical condition.

Participants also offered the opinion that these pictograms could be used not only by survivors but also as an educational tool to educate healthcare providers. Usually, during follow-ups, survivors meet with their specialist in accordance with NICE guidelines (NICE, 2002). However, these visits occur only once a year. If between these visits survivors encounter an issue with their treatment, they tend to consult their general practitioner (GP). GPs' knowledge was questioned by some participants, who felt that these pictograms could be a worthwhile tool, informing their doctor about survivors' experiences during hormone therapy. The use of these pictograms as an educational resource for survivors and healthcare providers will be discussed in more detail in the next chapter, where more information about their potential implementation will also be given.

In order to make the pictograms more understandable, each was designed with a picture and associated text. This is in line with Mayer's cognitive theory of multimedia learning, which recommends the combined use of different media to increase understanding (Dowse et al., 2011). The two principles in this theory which I followed in my design planning are the Multimedia Principle and the Spatial Contiguity Principle. The Multimedia Principle states that understanding is more achievable from words and pictures (multiple media) than from words alone. Having the text directly under the picture is in line with the Spatial Contiguity Principle, which states that having a picture and its associated text near each other helps users retain, understand and recall information (Dowse et al., 2011). The findings of this study support this, with all my participants understanding all pictograms perfectly regardless of their health literacy level.

Pictograms are quite beneficial to medication taking and can influence patients' adherence levels. They can do this by improving communication between patients and

their health care providers, and patients understanding.. Many studies have highlighted the importance of pictograms and how influential they could be. A literature review by Barros et al. (2014) assessed the importance of using pictograms in medicine. The study showed the positive effect of using pictograms on patients' education and their adherence. The study also highlighted the positive effects using pictograms have on patients' understanding of oral and written information. This is in line with the findings of Houts et al. (2006), Dowse and Ehlers (1998) and Clawson et al. (2012). I find myself falling into the same category, I am a strong believer in the importance of pictogram in healthcare before conducting this study. My beliefs now are much stronger, especially after listening to my participants and recording their responses for this study.

One of the strengths of this study derives from its sequential approach (see Figure 4-5), which allowed the design to be validated by healthcare professionals and researchers first. Also, by involving breast cancer survivors, it allowed the pictograms to be validated by actual experts who had lived or were living the experiences the pictograms were trying to portray. Another strength of this study is the inclusion of a graphic designer, which allowed me to create and convey experiences better, the skill of the designer proving very useful in complementing the texts and capturing the strength of the categories.

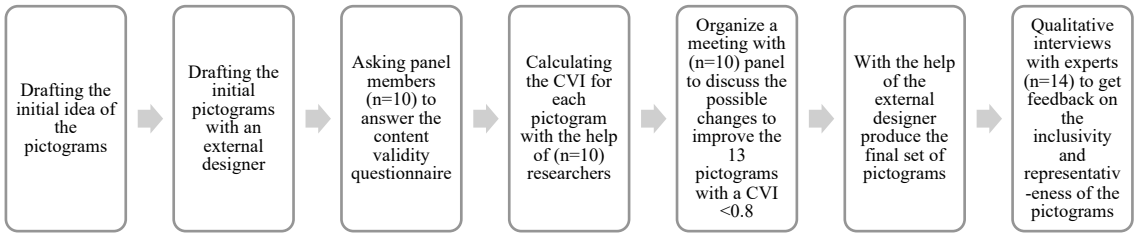


Figure 4-5: The process of designing the pictograms in summary

However, it is worth mentioning that this study has some limitations. The first is that the pictograms were not examined in a clinical setting to assess their utility in practice. Also, they were developed using categories derived from the results of my meta-synthesis that used quotations from previously published articles. So, questions about the pictograms'

inclusivity remain unanswered and need to be addressed. Future research should look at assessing these models against a full data set of interviews to make sure they are all inclusive and no experience is missed – this was indeed the rationale for my further work detailed in Chapter 6. Also, future research should evaluate the utility of the pictograms within a clinical setting to assess the benefits of using them on a larger scale. As detailed in the succeeding chapters, I was able to further amend these pictograms (Chapter 6) following my interview study (Chapter 5) in order to address the inclusivity question.

Chapter 5: Investigating adherence to hormone therapy in breast cancer survivorship: an interview study

5.1 Introduction

I start this chapter by providing here (see Table 5-1) a few definitions of some key terms I will be using throughout this chapter and beyond.

Table 5-1: Definition of terms used in Chapter 5 (Corbin et al., 2014; Charmaz, 2014).

Element	Description
Purposive sampling	Sampling is decided upon *a priori*, that is, before the researcher begins the data collection process.
Theoretical sampling	This is sampling for the purpose of focusing data collection and increasing the analytic abstraction of theory by illuminating variation and identifying gaps that require elaboration.
Data saturation	This is when new data do not add any further insights to the core categories and/or the discovery of additional properties for those categories.

In Chapter 3, I detailed my meta-synthesis using grounded theory synthesis to appraise, summarize and synthesize data from existing qualitative studies. This resulted in the development of three main categories: 1) 'Guided by the doctors: accepting the long-term prescription'; 2) 'Balancing priorities: adhering to the long-term treatment'; 3) 'Taking a chance: stopping the treatment early'. The core category explored whether and in what way the woman's decision to take the medication was a case of a "Hobson's choice or a horned dilemma?".

The three paradigm models were comprehensive and developed from the reported views and experiences of 610 women with a breast cancer diagnosis in 24 different studies, thus providing a generally more inclusive understanding of the phenomenon than any single previous published study. However, there were still some questions in need of answering about the validity of my models. It was important to me to test if the use of quotations (reported in the studies retrieve) versus full data sets of interviews (not reproduced within published studies) could be reconciled. The aim of my interview study therefore was to

validate and improve the grounded theory models illustrate in Chapter 3 and examine them against a full dataset of interviews, with the ultimate goal of creating an all-encompassing explanatory model of hormonal medication-taking in breast cancer survivorship.

5.1.1 Aim

To validate and improve the grounded theory models created in the meta-synthesis study and examine them against a full dataset of interviews with the ultimate goal of creating an all-inclusive explanatory model of hormonal medication taking in breast cancer survivorship.

5.1.2 Objectives

- Conduct in depth interviews with women who are breast cancer survivors and have taken or are taking adjuvant endocrine therapy.
- Validate and improve the grounded theory models created in the meta-synthesis study and the pictograms detailed in the previous chapter.
- Create an all-encompassing grounded theory of women's experiences with hormone therapy in the management of breast cancer.

5.2 The study methods

5.2.1 Materials

This study was reviewed by the University of Reading Research Ethics Committee and received a favourable opinion on the 18th of January 2018. I am going to start this part of this chapter from the beginning by showing the steps I took to receive the necessary approval. Before starting the study and in order to gain the necessary ethical approvals from the required organization, I identified the possible ethical issues and risks to the study participants that should be considered in a study such as this. The following issues were identified:

- I did not anticipate there being any more risk than the participants might experience during their daily lives. However, due to the nature of the

interviews and the condition under investigation, participants might experience some distress and anxiety. I therefore took extra precautions to make sure participant autonomy was respected and in the process of gaining their consent ensured that each participant understood their right to stop the interview, to refuse to answer any question they might find difficult, and to withdraw their consent at any time before, during or after the interview, without repercussions. I explained to each participant that if they agreed to participate but later changed their mind, their data would be removed from the study and destroyed; it was made clear that this would be possible up until the completion of the data analysis (i.e. three months after their interview date).

- Another factor taken into consideration was the possibility that participants might feel uncomfortable talking one-to-one with a male researcher (me) about a potentially sensitive subject. In order to avoid this, each participant was invited to attend the face-to-face interview with a trusted family member/friend; if someone preferred to attend on their own, it was agreed that the project supervisor, Professor Parastou Donyai, would at the participant's request attend the interview with me.

- Overall, we did not anticipate that the participants would be exposed to any harm. The only risk from a study such as this (i.e. in which participants are asked to talk about medication adherence) is the normalization of unhelpful behaviours, creating self-doubt or "labelling" individuals (e.g. as non-adherent), or indeed giving the incorrect impression that advice would be provided. For this reason, I made it very clear in the information sheet, and also in the interview itself, that I was acting as a researcher (the researcher is not registered to practise in the UK) trying to understand medication-taking behaviour, and not making judgements about what is the right or wrong behaviour. The language used in the interviews was sensitive and considerate. If a participant asked for advice, they were signposted to their practitioner or pharmacist. In addition, the debrief statement informed participants that the study was about medication-taking and that if they did talk about instances

where they have not taken or do not take their medication as prescribed, then this is something they should discuss with their prescriber.

- To make sure participants' identity remained confidential and private, I made sure they would not be personally identifiable; any audio-recordings of the interviews were stored on a password-protected university drive as encrypted files accessible only by myself and my supervisors. The interviews were transcribed by a transcription agency. The Transcription Agency is the preferred supplier of transcription services to the university and has a secure file transfer process as well as certificates to verify data handling in accordance with the Data Protection Act (see Appendix 5); transcriptions are stored as MS Word files with no indication of the participant's name or any information that might identify them. Like the audio recordings, the Word files were stored on a university shared drive as encrypted files only accessible by myself and my supervisors. All data collected (e.g. participant interviews) was anonymized so that they could not be traced back to the participant.

- To minimize misrepresentation and make sure of the accuracy and representation of the used information, participants were provided with a copy of the transcript if they wished. In addition, all participants were sent a copy of the final report of the main findings per their request.

5.2.1.1 Interview guide

As already mentioned, data were collected using single interviews with breast cancer survivors, the interviews being conducted either face-to-face or by telephone. Before starting the interviews I devised an interview schedule to guide the conversation. An important part of qualitative research, the interview schedule is a guide to make sure all topics are covered and addressed during the conversation. An interview schedule is also a requirement of the University of Reading ethics approval procedure. The Research Ethics Committee requires an interview schedule to make a judgement about the nature of the questions being asked and to make sure all potential issues that might arise from asking these questions are identified and addressed.

All questions in the interview guide were made open-ended to allow participants to answer in their own words. Questions were carefully prepared to avoid any possible misunderstandings and worded to avoid showing any judgment. Any question I felt to be leading respondents one way, or another was replaced to ensure participants' responses remained uninfluenced by the question itself. In addition, all questions were couched in layman's terms to ensure they would be understood by everyone, irrespective of their level of education or health literacy. Moreover, I prepared follow-up questions to allow me to keep the conversation going and gain more information about the phenomenon under investigation.

The interview schedule consists of six parts, the first part of which is shown in Box 5-1. The interviews began with general questions unrelated to the research, the aim being to establish rapport with the interviewee. Next I asked some easy direct questions about the participant's age and the hormone therapy medication they were either taking or had taken in the past. The second part consisted of an introduction to my research, explaining the form the interview would take (with an opportunity for the participant to ask questions), and lastly gaining the participant's consent to record the interview, as shown in Box 5-2. I then started the recorded interview with questions about the three stages of the treatment as identified in the meta-synthesis chapter. All questions were developed using the information obtained from the grounded theory models developed from the meta-synthesis study in Chapter 3. I began by asking questions about the start of the treatment, covering the prescription stage of hormone therapy as shown in Box 5-3. Next came questions about the adherence stage of the treatment as shown in Box 5-4. If the participant had stopped taking the treatment I followed up with the questions about stopping the treatment as shown in Box 5-5.

I then moved on to the second part of the interview, where I showed the participants the pictograms mentioned in Chapter 4, that were developed from the grounded theory models of Chapter 3. I started by explaining the pictograms and how I created them, then moved on to explain each and every one of the pictograms, all the while encouraging the participants to comment, ask and share anything they might remember. After finishing each pictogram I asked each participant a general question about whether they had anything to add and whether the diagram reflected their personal experience. I did this

for all pictograms as shown in Box 5-6 and Box 5-7. I then explained the core category I developed in Chapter 3 and asked them whether or not it represented what they had experienced or were still experiencing, as shown in Box 5-7. Finally, I ended the interview by thanking the participants, allowing them to add any last remarks, explaining what I intended to do with the information they had provided me with and reminding them of their rights as shown in Box 5-8.

The development of the interview schedule was based on multiple meetings between myself and my primary PhD supervisor. In these meetings we reached an agreement on the sequence and wording of the questions. The only thing left was the presentation of the pictograms. To train for this I presented the pictograms and the created models in five different settings in the School of Pharmacy at the University of Reading, under the supervision of my primary PhD supervisor. Also, my supervisor was present during the first interview I conducted, in order to provide feedback on my interviewing skill and make sure I was ready to conduct the interviews by myself, and to assess whether any of the questions in the interview guide required any modification.

Box 5-1: Part 1 of the interview schedule (establish rapport)

Step 1: Establish rapport:

Hello, my name is Othman AlOmeir. I am a 3rd year PhD student at the University of Reading department of Pharmacy Practice.

First of all, thank you so much for accepting our invitation, it is greatly appreciated.

- **I hope you found the place OK?**
- **How are you today?**
- **I should talk about something not related to the study like the weather or transport to ease the participant into the conversation.**

I should let the interviewee speak without interruption.
I should communicate empathy.

Information I need to know before the interview:

- Can I just ask what age band you are? (18-29) (30-39) (40-49) (50-59) (60-69) (>70)
- What hormonal treatment were you prescribed?
- How long they took it? Or if they are still taking it?
- Did they finish the whole duration of the treatment? If not, did they stop by themselves or by the help of their health care provider?

Box 5-2: Part 2 of the interview schedule (explain the aim of the interview)

Step2: Explain the aim of the interview:

My project is about studying the views and experiences of women taking hormone therapy after a breast cancer diagnosis. What we want from this study is to understand the range of views and feelings women express during a hormone therapy prescription and throughout the treatment. To do so I am going to be asking you a set of questions.

After answering the questions, I will be showing you some diagrams that I have created from the literature review I have conducted before, in an attempt to understand what women go through while taking these medications.

Your views and experiences will help me validate and expand these models by better understanding your journey. Your feedback will help us better understand women's views and experiences during hormone therapy treatment. So, thank you so much for your participation, it is greatly appreciated.

Before we start, I have sent you a copy of this, but I would like to go through the important elements with you.
Why I am conducting this project?
PhD student > Pharmacist in Saudi Arabia > gain insight into UK health system > beneficial to my own carrier and hopefully to women going through a breast cancer diagnosis in Saudi Arabia.

Can I check with you how long you have, and I will try to make sure we finish at time?

- **Do you have any questions at this point?**
- **Then can I please collect a signed consent form from you?**
- **Is it Ok with you if I audio record the interview? It will be really helpful because I tend to forget things, and this will give me an accurate record. The transcript will be completely anonymised and any reference that could identify you will be removed.**

Box 5-3: Part 3 of the interview schedule (interview – the start of the treatment)

Step 3: start the interview: (reinstatement of context and initiating a free report)

This interview consists of four parts. The first part is about the start of the treatment.

1. <u>Start of the treatment (Prescription):</u>

I am going to be asking you some questions about the time you were prescribed hormone therapy.

- What can you tell me about the day you were prescribed hormone therapy?
- What were the thoughts as the oncologist was prescribing the hormone treatment?
- Did you get a chance to ask questions?
- What was your main reason for taking the treatment?

Interested in mentioning the transition into a new stage of the treatment, fear of recurrence, fear of the side-effects, information and knowledge about the treatment, trust and communication with health care provider.

Questions to keep the conversation going:

- What were your initial thoughts about the medications?
- Were all your questions answered?
- How did you feel as you were leaving the oncologist office?
- What hormone therapy they were prescribed?
- How long were you required to take it?

Now we are going to move to the second stage of the treatment.

Box 5-4: Continuation of part 3 of the interview schedule (interview – adhering to the treatment)

2. <u>During the treatment (Adherence):</u>

I am going to be asking you questions now about your experience with hormone therapy. You were asked to adhere to the treatment for (duration of time). Please at your own pace and time, tell me everything that comes to your mind in term of taking your medicine during that time.

- How was your experience with (the treatment)?
- Did you need to do anything different to adapt to the treatment? (adaptation and lifestyle modifications)
- How did you feel about the treatment?
- How did the people around you respond/ if at all? (family, friends, co-workers, peers)
- Did your perception of the treatment change as the years have gone by?
- How was the professional support throughout the treatment? (oncologist, GPs, nurses, pharmacists, support groups).
- How would you describe your relationship with your health care provider?
- What can you tell me about the side-effects?
    - Were they as expected or were you surprised by them?
    - Did you take anything to manage the side-effects? (Alternative medicine?)
- When you have a question you would like to find an answer for, what is your main source of information?

Adherence questions if not mentioned before:

Have you ever forgotten to take the treatment as prescribed?

If yes

How did you feel when that happened?

If no

Did you use any technique to make sure to always remember?

Have you ever decided to take a break from the treatment or thought about it? (drug holiday?)

What can you tell me about your experience with filling in a prescription?

A stand-alone Question before moving to the next stage of the interview for women who have finished the whole duration of the treatment:

- **As you reached the end of the treatment, were you informed by anyone that you can stop the treatment now?**
- **What happened when you reached the end of the treatment?**
- **What was that transition like for you?**

If the participant is still taking the treatment or has finished the whole duration of the treatment move to step no. 4
If the participant stopped the treatment prematurely move to no. 3 (stopping the treatment)

Now we are going to move to the third stage of the treatment.

Box 5-5: Continuation of part 3 of the interview schedule (interview – stopping the treatment)

3. <u>Stopping the treatment:</u>

You took the treatment for (certain duration) and then decided to stop. Please at your own time and pace, what can you tell me about your decision to stop?

- Why did you decide to stop the treatment?
- How did you feel when you took the decision to stop the treatment?
- Did you discuss your decision with anyone?

Interested in learning the reason(s) behind stopping the treatment.

Now I am going to be moving to the last part of the interview.

Box 5-6: Part 4 of the interview schedule (interview – 1st and 2nd models discussion)

Step 4: Validation of grounded theory models

In this last part I am going to be showing you some diagrams that I have created using data I collected from published studies. Please remember there are no wrong answers. Nothing you say will hurt my feeling, so I want to feel free to tell any and everything that comes to your mind.

1. **First diagram:**
   Please, would you mind looking at this diagram?

   Give the participant the first diagram "Diagram 1 (The paradigm model for the category 'The treatment of breast cancer: prescription of a long-term drug')"
   Explain the paradigm model.
   Do you have any questions you would like me to answer?

   I am interested in what you are thinking as you look it over? Please take as much time as you need, as you are looking at it tell me any thoughts that goes through your mind?

   - Tell me what you are thinking? OR
   - What thoughts are going through your mind right now?

   After looking at the diagram, do you have any other thoughts from your personal experience you would like to share? Did you remember something else you would like to tell me?

   Do you think the diagram is a reasonable representation of your own story, even if not everything in the diagram applies to you?

2. **Second Diagram:**
   Please, would you mind looking at this diagram?

   Give the participant the second diagram "Diagram 2 (The paradigm model for the category 'The treatment of breast cancer: adhering to the long-term treatment)"
   Explain the paradigm model.
   Do you have any questions you would like me to answer?

   I am interested in what you are thinking as you look it over? Please take as much time as you need, as you are looking at it tell me any thoughts that goes through your mind?

   - Tell me what you are thinking? OR
   - What thoughts are going through your mind right now?

   After looking at the diagram, do you have any other thoughts from your personal experience you would like to share? Did you remember something else you would like to tell me?

   Do you think the diagram is a reasonable representation of your own story, even if not everything in the diagram applies to you?

Box 5-7: Continuation of part 4 of the interview schedule (interview – 3rd model and core category discussion)

3. **Third Diagram**

Please, would you mind looking at this last diagram?

Give the participant the third diagram "Diagram 3 (The paradigm model for the category 'The treatment of breast cancer: Stopping the long-term treatment')"

Explain the paradigm model.
Do you have any questions you would like me to answer?

I am interested in what you are thinking as you look it over? Please take as much time as you need, as you are looking at it tell me any thoughts that goes through your mind?

- Tell me what you are thinking? OR
- What thoughts are going through your mind right now?

After looking at the diagram, do you have any other thoughts from your personal experience you would like to share? Did you remember something else you would like to tell me?

Do you think the diagram is a reasonable representation of your own story, even if not everything in the diagram applies to you?

4. **Core Category:**

Please, would you mind looking at this last diagram?

Explain the core category and how I came to it as a conclusion.

I am interested in what you are thinking about the core category? Please take as much time as you need, as you are looking at it tell me any thoughts that goes through your mind?

- Tell me what you are thinking? OR
- What thoughts are going through your mind right now?

Do you think the core category is a reasonable representation of your own story?

Box 5-8: Part 5 of the interview schedule (end of interview)

Step 5: The ending of the interview:

- Now we have reached the end of the interview.
- You have given me some interesting insight into women adherence to hormone therapy in breast cancer.
- Thank you so much for taking the time to talk to me.
- Do you have any questions you would like to ask me or any last comments?
- I think I have all the information I need.
- What I will do next is to transcribe this interview and then analyse the text.
- Then I will write up the results of my work and produce a report.
- I am happy to share the results of this study with you should you want to read it.
- Many thank again – the interview is now formally at an end and I will switch off the audio-recorder.
- Confirm email address for the Amazon voucher to be sent.

5.2.1.2 Participant's information sheet, recruitment poster and consent form.

The other requirements for the University of Reading ethics approval procedure are an information sheet and a consent form. Therefore, by following the guidance in the University of Reading Research Ethics Committee website I started preparing the required documents (University of Reading, 2012). The recruitment poster (see Appendix 6) was sent to university staff and breast cancer support groups around the UK. If anyone contacted me showing interest in joining the study, I replied to them with a copy of the information sheet giving more detailed information about the study (see Appendix 7), including answers to the following questions:

- Why am I conducting this project?
- What will you have to do if you agree to take part in this project?
- Will you receive any payment for participating in this project?
- How much time will this project take?
- Will your personal information and participation remain confidential?
- What are the advantages of taking part in this project?
- What are the disadvantages of taking part in this project?
- What will happen to the results of the study?
- Do you have to take part in this project?
- What if there is a problem?

- What happens now?
- Who is organizing and funding the research?
- Who has reviewed the study?

General background information about my area of interest and contact details for myself and my PhD supervisor were also provided.

One of the requirements of conducting any research with human participants is getting their consent in written form. Therefore, following the guidance on the University of Reading Research Ethics Committee website I prepared a consent form (Appendix 8). Also, at this stage, I prepared the invitation letter that I planned to send in the recruitment email to University of Reading staff and the breast cancer support groups (see Appendix 9).

After preparing all the required documents, I filled out the University of Reading Research Ethics Committee application form (see Appendix 10) and included the interview schedule, recruitment poster, information sheet, consent form and invitation letter as well as a detailed protocol of the study. These were reviewed by the University of Reading Research Ethics Committee and received a favourable opinion on 18 January 2018 (see Appendix 11).

5.2.2 Setting and participants

My original ethics application stated that recruitment would commence with an email sent to breast cancer support groups in the Reading area. However, I decided to begin recruiting within the University of Reading first by sending a recruitment email to University of Reading staff. To this end, I sent an amendment request (see Appendix 12), receiving a favourable opinion on 16 November 2018 (see Appendix 13).

In data collection I used the theoretical sampling technique, in line with the Straussian grounded theory methodology. Theoretical sampling differs from other conventional data collection techniques, allowing the researcher more freedom in recruiting. Before I started interviewing participants I identified the population I was interested in, namely women diagnosed with breast cancer who were/had been receiving a prescription for an

oral hormonal medication for the long-term management of the condition. The setting I was going to recruit from originally was breast cancer support groups; however, this changed to recruiting from the University of Reading lists in the first instance to provide me with some experience locally, before I reached out to other women through support networks.

This freedom in data collection, permitted by grounded theory methodology, allowed me to follow the leads I noticed during the interviews and to continue examining them by directing my research toward these new areas of interest. Following the theoretical sampling technique, my process was as follows. I started by collecting data which was then analysed to develop concepts; these were then used to develop questions, which in turn were used to collect data from other participants in order to learn more about the concepts in question and strengthen the categories. This process continued until data saturation – the point at which no new questions can be developed, all necessary data has been collected and all questions have been answered sufficiently – was reached (see Figure 5-1).

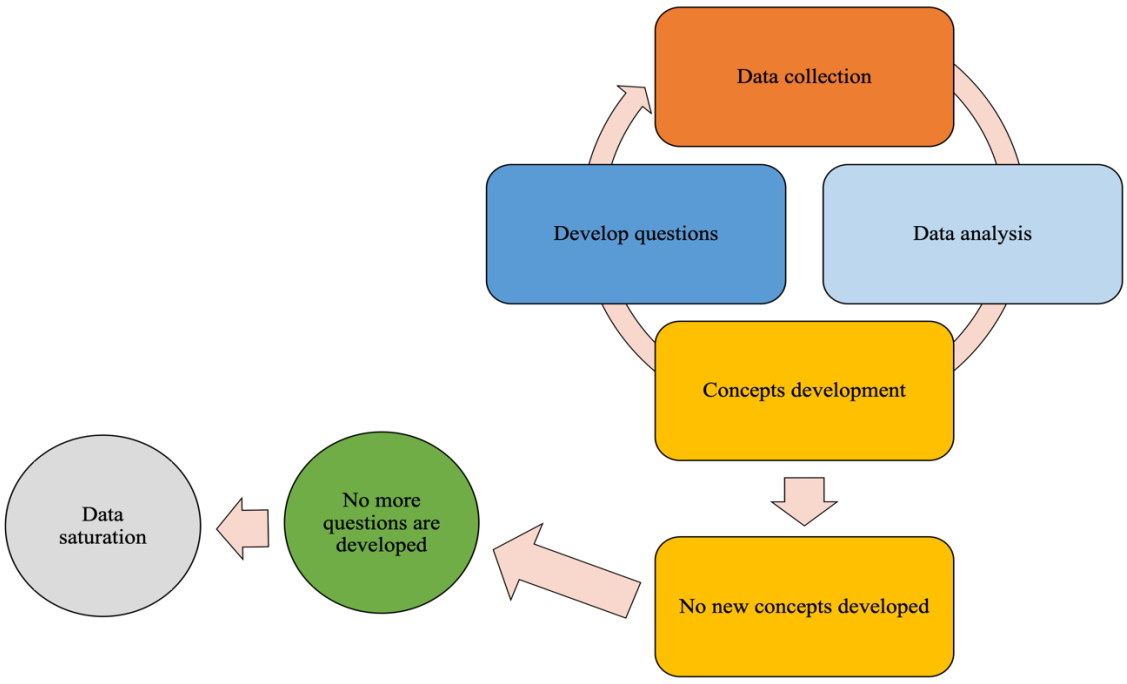


Figure 5-1: The process of data collection and identifying data saturation.

In addition to theoretical sampling, I used purposive sampling. Purposive sampling is about selecting the participants based on population characteristics. In my research, I used

purposive sampling techniques to categorize those taking part according to the following criteria: age, level of education, treatment duration and the medication they had been/were taking.

As mentioned before, I started recruitment within the University of Reading by sending a recruitment email and the recruitment poster to the university staff, using the university's own email system. I received multiple replies enquiring about the study, to which I replied, attaching a copy of the information sheet. As a result of this exercise I was able to recruit a total of nine interviewees (Participant 1 – Participant 9), eight of whom were University of Reading staff, with one volunteer being a relative of a staff member.

I then set out to recruit more participants by sending an invitation letter to multiple breast cancer support groups in the Reading area (see Table 5-2). Though the response was poorer and more sluggish than anticipated, through this route I was able to recruit a further five participants (Participant 10 – Participant 14).

As already mentioned, my inclusion criteria were driven by the research itself and the results of my prior analysis. Generally speaking, however, women diagnosed with breast cancer who were or had been receiving a prescription for an oral hormonal medication for the long-term management of the condition, such as tamoxifen and aromatase inhibitors (anastrozole, exemestane, letrozole), were deemed suitable for inclusion. On the other hand, women in an acute state of illness preventing them from taking part in the interviews, those unable to provide consent by themselves due to health issues or a language barrier, and breast cancer survivors who had not been prescribed adjuvant endocrine therapy, were deemed unsuitable for the study.

Table 5-2: List of the breast cancer support groups contacted for recruitment freely available on the internet (Macmillan cancer support)

Name of the organization	Website	Address and contact information
Three Counties Breast Cancer Support Group	NA	Jackie Wetherell 01344774149 jackiew@btinternet.com
Newbury Breast Care Support Group	www.nbcsg.com	Regency Park Hotel, Bowling Green Road, Thatcham RG18 3RP Maureen Le Du 07795003040 sefton@maureenledu.plus.com
Basingstoke Breast Cancer Self Help Group	www.basingstokebreastcancer.org.uk	The Ark Conference Centre Dinwoodie Drive, Basingstoke, Hampshire RG24 9NN Mrs Angela Bennett 07939 641187 basingstokebreastcancer@gmail.com
Bosom Friends – The Oxfordshire Breast Cancer Support Group	www.bosomfriends.org.uk	Jan Backhouse 01844 290362 janback@btinternet.com
Ashford Breast Cancer Support Group	www.abcsupportgroup.org	Sue Watts 07805033848
Breast Friends Aylesbury	www.breastfriends-aylesbury.org.uk	5 Potash Close, Haddenham, Bucks. HP17 8JY Jan Backhouse 01844 290362 07743450833
Trojans Breast Cancer Support Group	www.trojansupport.me.uk	Wendy Pollard 01923 266728 info@trojansupport.me.uk
Cancerkin (Patient Support Group and Young Women's Support Group)	www.cancerkin.org.uk	Victoria Todd 020 7830 2323 info@cancerkin.org.uk
Chrysalis Breast Cancer Support Group	www.chrysalisbreastgroup.org.uk	Liz Darragh 01737 768511 care@chrysalisbreastgroup.org.uk The Olive Tree, Crawley Hospital West Green Drive Crawley, West Sussex RH11 7DH
Living with Secondary Breast Cancer − Coventry	www.breastcancercare.org.uk	0345 077 1893

		secondaryservices@breastcancercare.org.uk
Breast Friends Solihull	www.breastfriends-solihull.org.uk	12 Perryford Drive Solihull B91 3XE 0800 1313 500 b.friends@blueyonder.co.uk
1066 Pink Ladies (The Hastings and Bexhill area)	1066pinkladies.org.uk	Pat King 01424220665 info@1066pinkladies.org.uk The Pelham, Holliers Hill Bexhill-on-Sea TN39

5.2.3 Study procedures

All nine participants identified by the recruitment email I sent through the University of Reading email system were interviewed face-to-face in a private room on the University of Reading campus. However, of the five participants identified through breast cancer support groups, two were interviewed face-to-face, while the other three were interviewed by telephone from a quiet and private room in my house. All interviews lasted between 40 and 85 minutes, with an average length of 59 minutes.

The interviews started with me explaining the purpose of the interview and answering any questions the participant might have. I then ensured I had the signed consent (by email in case of telephone interviews) and asked them for permission to start audio-recording. At the end of the interview I asked the participant if they wished to add or tell me anything, before asking their permission to stop the recording. Each participant was later sent a £20 Amazon voucher (using the email address provided in their consent form) as compensation for taking part in the study. Each participant was interviewed only once.

All interviews were audio-recorded using a digital audio recorder. The recordings were then moved from the recorder to a secured file (accessible only by myself and my supervisor) on a university computer. As mentioned before, the recordings were then transcribed verbatim into MS Word files by a transcription agency. I then made sure the recordings matched the transcripts exactly and deleted any names or information that could lead to the identification of the participants. All participants were given a code based on the sequential order of their interview (Participant 1 – Participant 14; see Table 5-3).

Table 5-3: Participants codes and characteristics

Participant no.	Participant code	Age group	Medication history	Duration taking the treatment	Interview duration	Interview type
Participant 1	**Interview 1**	50−59	Anastrozole	Stopped after 5 years	45:21	Face to face interview
Participant 2	**Interview 2**	60−69	Anastrozole	16 years on the treatment and still continuing	42:53	Face to face interview
Participant 3	**Interview 3**	50−59	Tamoxifen then switched to Exemestane	5 years on the treatment and still continuing	55:53	Face to face interview
Participant 4	**Interview 4**	60−69	Anastrozole	4 years on the treatment and still continuing	50:48	Face to face interview
Participant 5	**Interview 5**	50−59	Tamoxifen then switched to Letrozole	Stopped the treatment after 10 years – 5 years on each treatment	41:07	Face to face interview
Participant 6	**Interview 6**	50−59	Anastrozole	4 years on the treatment and still continuing	46:14	Face to face interview
Participant 7	**Interview 7**	50−59	Tamoxifen	8 years on the treatment and still continuing	53:18	Face to face interview
Participant 8	**Interview 8**	40−49	Tamoxifen	2 months on the treatment and still continuing	39:38	Face to face interview
Participant 9	**Interview 9**	60−69	Anastrozole	6 years on the treatment and still continuing	1:12:28	Face to face interview
Participant 10	**Interview 10**	50−59	Anastrozole	18 months on the treatment and still continuing	52:51	Face to face interview
Participant 11	**Interview 11**	50−59	Anastrozole	5 years on the treatment and still continuing	1:21:35	Phone interview
Participant 12	**interview 12**	50−59	Tamoxifen then switched to Letrozole	3rd year on the treatment	1:04:37	Phone interview
Participant 13	**Interview 13**	>70	Tamoxifen then switched to Anastrozole	Stopped the treatment after 8 years	1:24:31	Phone interview
Participant 14	**Interview 14**	>70	Tamoxifen then switched to Letrozole	Stopped after 5 years and refused to continue further	1:22:49	Face to face interview

5.2.4 Data analysis

As with the data analysis described in Chapter 3, I adopted the Strauss and Corbin method of grounded theory. As has been mentioned, grounded theory is not intended to be a linear process. Although it might seem that the process followed was linear according to my descriptions here, this is because of academic conventions. The data analysis process followed a sequence, as shown in Figure 5-2, however, the analysis process moved from one level of abstraction to another, moving back and forth between the various levels of coding in a non-linear matter.

I will describe in this section how the data was deconstructed, reorganized and coded at multiple levels to provide an understanding of women's experience of hormone therapy treatment. In addition, I will give a few examples of the coding process to explain the procedure I followed. The first thing I did before starting the analysis was read the transcripts multiple times to familiarize myself with the data. Then, following the Strauss and Corbin method, I started coding the data at the three levels mentioned below: open, axial and selective coding.

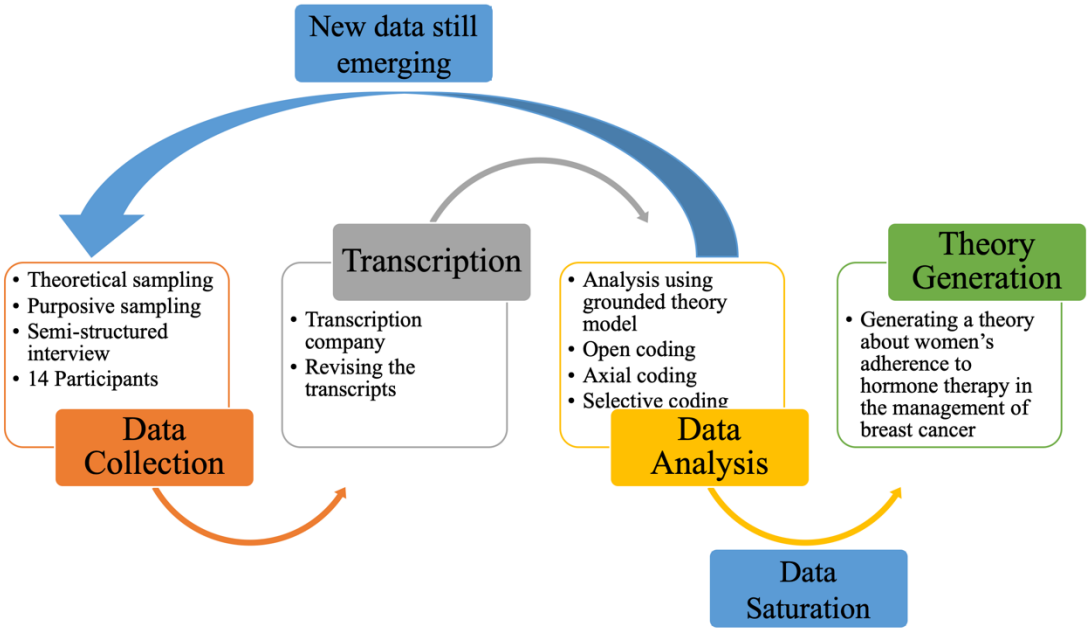


Figure 5-2: The process of data analysis.

5.2.4.1 Open coding

I started the open coding process by breaking the data into sets of concepts. The concepts I used in the beginning were similar to those used in Chapter 3 as the work covered similar topics. The line between codes and categories was not as distinguished as it was in Chapter 3, due to the fact that the categories had previously been defined. The open coding process at this stage was thus a combination of inductive and deductive thinking. The challenge here was trying not to force the data into the set of concepts developed before, instead allowing it to fit new concepts (if possible) and tell the story the participant was trying to convey.

Thus, after analysing the data using the preconceived categories, the next step was to go back to the data and start the brainstorming stage to develop new concepts and categories, if possible. I started looking at what I might have missed and what new low-level concepts could be developed, asking "What is going on here?", "Why?", "How?" and "Where?", seeking to empathize with my participants, capture what they were going through and "walk a mile in their shoes". The concepts used at this stage are shown in Appendix 14.

Box 5-9: Summary of the open coding process

Level 1: Open coding

- Breaking the data apart.
- Identifying concepts that describe the raw data.
    - Brainstorming.
    - Questioning the data.
    - Making constant comparison[s].
    - Reflective thinking.
- Deciding on a set of possible categories.
- Discuss the finding with my primary PhD supervisor.
- Directing the theoretical sampling/purposive sampling process for the next interview (if needed).

5.2.4.2 Axial coding

As with the analysis process set out in Chapter 3, the axial coding process in Corbin and Strauss's grounded theory is about integrating the concepts into the paradigm model. As previously mentioned, the paradigm model consists of causal conditions, actions/interactions and consequences, and attempts to identify the process in the form of "If *this* happens, I do *this* in the anticipation that *this* will happen". Due to the fact that I had already developed the paradigms described in Chapter 3, the line between open coding and axial coding was more blurred in this element of my study. The codes I used in the open coding process fit the category in the paradigm, so open and axial coding were not just simultaneous but also shared a lot of similarities, as can be seen in Appendix 14. New categories were developed further and used to drive the theoretical sampling process, thus influencing the direction of recruitment and future interviews. The full models are presented in the Results section (5.3) of the present chapter.

Box 5-10: Summary of the axial coding process

Level 2: Axial coding

- Identifying the causal conditions, actions/interactions and consequences.
- Integrating the concepts into categories.
- Developing the relationship between the different categories.
- A mix of both deductive and inductive coding to create the categories.
- Creating the diagram that show the links and the flow of the process under investigation.
- Discussing the finding with my primary PhD supervisor.
- Directing the theoretical sampling/purposive sampling process for the next interview (if needed).

5.2.4.3 Selective coding

The selective coding process is about bringing everything in the analysis under an umbrella called the "core category". The core category I arrived at was "Hobson's choice or a horned dilemma?". This was developed in Chapter 3 to capture the combined experiences of the different participants. At this stage I examined the core category's ability to explain new data. All new data, new concepts and categories were checked for their compatibility with the core category. The core category is discussed further in the Results section, which follows.

Box 5-11: Summary of the selective coding process

Level 3: Selective coding

- Refining the theory
- Linking the new categories around the core category.
- Examining the created theory and core category against the collected data to make sure the theory is all inclusive.
- Checking for any gaps in logic.
- Explaining the phenomenon under investigation.
- Discussing the finding with my primary PhD supervisor.
- Directing the theoretical sampling/purposive sampling process for the next interview (if needed).

5.3 Results

As with the Results section in Chapter 3, the participants' journey about to be described is divided into the following three parts: 'Guided by the doctors: accepting the long-term prescription'; 'Balancing priorities: adhering to the long-term treatment'; and 'Taking a chance: stopping the treatment early'. I begin by presenting the results of my own interview study, before showing how this new data affected the grounded theory models I created in Chapter 3. The final, all-inclusive models and the modifications I had to make in order to accommodate the new information, will be presented after the set of results to which they relate.

5.3.1 Guided by the doctors: accepting the long-term prescription

5.3.1.1 New treatment stage

The women participants recognized the transition into a new stage of the treatment and talked about how that transition made them feel. Some felt "isolated" and "on your own", while others, while recognizing the change "did not think much of it". While some of the women spoke of feeling alone, they differed about how this made them feel. Some felt the transition was easy while others found it hard, though still managing to cope with it.

> "You're not necessarily thinking clearly and you're also, and I think it's once you pull away from the regular hospital visits and the treatment and things and reviews that you do feel a bit more isolated and on your own in terms of, I suppose, support. It didn't inconvenience me in any way, so I suppose I found the transition quite easy." Interview 1

> "Suddenly you're just completely on your own, yes, and it is hard because you're taking new medication, you're just getting over the chemotherapy, you've had phone calls from your oncology team, from the chemo team then all, then that's it you're just left to get on with it really." Interview 3

> "I think it could be, transitions with ease but not necessarily, it affected my life but I, but this is my face, but it's not, it hadn't been easy, so you can cope even though it's bloody hard, yeah." Interview 5

> "But the transition, to be honest, I didn't think much of it." Interview 8

5.3.1.2 The prescription visit experience

The first prescription visit (when the hormonal therapy is first prescribed) proved to be different from one woman to another. Some felt the experience was positive, while others had issues. One woman mentioned the lack of time in her prescription visit, talking about not actually being able to see her healthcare provider for long enough to go through everything she needed to relate to her treatment.

> "I did ask but not many because my appointment was quite short to be honest, so I didn't have much time with the doctor to go through everything." Interview 8

Another issue raised was that of healthcare providers expecting women to make decisions about the treatment on the spot, without having enough time to process what they are going through.

> "I was expected to make a decision there and then and so it was quite intimidating really." Interview 1

> "He was saying, it was quite quick, do you have anything else? So I didn't have enough time to process it myself and then ask, so yeah not really then." Interview 8

Due to lack of time and how overwhelming the experience could be, women reported their inability to ask questions during the prescription visit. When asked about whether or not she had been given a chance to ask questions, one woman replied:

> "Not really. No. That was it. That was the treatment and that's what I had to go on." Interview 6

Of course not everyone reported similar experiences. To some, the process was positive, with opportunity being given to ask and receive answers to whatever questions they had.

> "Yeah, yeah it was a very, yeah I could just ask questions of the oncologist." Interview 7

> "Yes, I was able to ask questions." Interview 9

> "Yes they, I must admit the consultants were really, really good, even if it meant the clinics were late, they didn't ever rush you, so there was time to ask questions." Interview 12

5.3.1.3 Knowledge and information

Women at this stage of the treatment receive a lot of information, both verbally from the oncologist and cancer nurses, or in the form of leaflets. Being bombarded with a lot of information about breast cancer and hormone therapy made some women in my study feel overwhelmed and confused.

> "The leaflets that come with the tablets because sometimes, they can be a bit overwhelming. There's too much information on there. This might happen, that might happen, this effect might happen, they could do this or they could do that. You need somebody that's going to talk in, probably sounds like I'm being a bit ignorant here, but in my layman's terms? You know, in a vocabulary that I'm going to understand without having to sit and analyse and try and make out what these instructions sheets mean." Interview 6

> "I was given a lot of, this includes all information about, I was given lots of information, booklets from Macmillan, from the hospital, everything all about the treatment." Interview 9

Another participant talked about how overwhelming she found not the amount of information *per se*, but rather the whole experience, the combination of finishing the

initial treatment and transitioning into a new stage, the feeling of everything coming together at once.

> "I don't think the amount of information was necessarily too much because it's about one lot of treatment. But when you've gone through operations, chemotherapy, radiotherapy and your head is full of information, maybe it's just the tip of the iceberg and you just don't take in quite so much. I know for me, it was just kind of, what's next, what's next, what's next, you understand that these things have to happen and people take you through them but you just think, yeah that's fine, let's just get on with it. So I think yes, overwhelmed about the information they gave me on the tablets, probably not about that, but overwhelmed by the whole experience, so that my understanding was maybe a little bit not as good as it could have been." Interview 12

Some women really valued receiving the large amount of information, dealing with it well and feeling it helped inform their decision about whether or not to go ahead with the treatment.

> "No I think the information's been, all my care's been brilliant." Interview 10

One participant, asked whether the information she received was too much, answered in the affirmative but nevertheless used it as a driving force to look beyond what she was given and identify further knowledge.

> "Yes, yeah. And then I read, when you're academic you'll just go online and then just read whatever is out there." Interview 8

Another participant talked about receiving too much information and the importance of support in dealing with it, talking how having her husband with her during the prescription visit helped her to remember and deal with the amount of information she received.

> "Yes. I was quite lucky, that I think, I had a lot of information, perhaps a bit too much maybe if anything, but my husband went to all the appointments with me, so there was two of us to listen." Interview 2

While some women received a lot of information, too much in some instances, others complained about not receiving enough.

> "First of all they said you'd be on it for five years and, but they don't really explain. I didn't really know who to ask because, as I say, the oncology team are quite rushed, and you've gone through your treatment, so you just feel as if they're giving you them." Interview 3

> "I wished it had been explained a little bit more, with the side-effects of them. What to expect and also, whether there was any other options of drugs that I could have taken." Interview 6

Others preferred to be "spoon fed" information gradually, fearing they would be overwhelmed if given it all at once.

> "They didn't tell me all of that to begin with and afterwards I thought, I felt as though they should, but I think they do that so that you're not too overloaded with everything and they just, sort of slows it, well you're going to have to take this medication for ten years. Maybe if they told you all that at the beginning it would be too much to cope with. I was a bit spoon fed, which I think was probably the best thing really." Interview 10

While healthcare providers often try to give patients as much information as they can, without focusing on the patients' personal preference, identifying each patient's needs and health literacy level is indispensable in delivering a good service. One participant spoke of the need for a tailored way of delivering information in ways suited to each woman's particular needs.

> "So it's too much information in one way and not enough in another I think, it's an imbalance. It's not tailored at all. And a lot of it's very medicalized, the information that you get. And that's alright for me, but it's not alright for a lot of people." Interview 14

When participants were asked about their primary source of information, and who they would contact if they needed questions answered in order to make informed decisions, their responses varied. While some contacted their healthcare provider, others went online to search for answers. "Doctor Google", a term used by one participant, is mentioned multiple times in the data. Another participant talked about identifying academic papers, still another about breast cancer and other cancer-specific websites as their primary source of information.

> "There's doctor Google of course − it's huge isn't it?" Interview 3

> "I'll look at Google Scholar, and look at academic ones, so I will try and go into medical journals, actually, because I can kind of understand most of what they say, although I don't understand the medical language. But the introduction, the conclusion, you can get a sense of that." Interview 4

> "I went to breast cancer, there is a website breast cancer and then there is another one, the Macmillan one." Interview 8

Support groups were mentioned as a source of information by some women. After the diagnosis and the consultation, some women contacted their local breast cancer support group in an attempt to learn more about the treatment and their options, especially if their healthcare provider had left them confused or uncertain.

> "When they're diagnosed the surgeon or the oncologist gives them as much information as they can, obviously, but unfortunately, a) you don't always take it in and b) they don't give you a lot of information about taking Arimidex or tamoxifen, simply to take it and it will help with trying to prevent it. So that's about as much as you get these days and they just, they don't even say, make sure

you read the leaflets, they, which would just take a moment or two. I recognize timing is always a problem with the consultants but it would be a good idea just to emphasize the fact they should read them. Most people would recognize that but you're not thinking very straight when you've had a diagnosis of breast cancer." Interview 13

5.3.1.4 Delaying the start of the treatment

When asked about whether or not they thought about delaying the treatment, most participants said no, some making clear their wish to start it as soon as possible.

> "It wasn't something I considered, delaying treatment. I just wanted to get through the treatment and get back to work." Interview 1

> "I was very keen to get on with it." interview 2

One participant mentioned taking a break for two or three days before starting the hormonal therapy treatment, after getting her healthcare provider's approval. To her, the priority was going back to her normal, medication-free life for a couple of days before embarking on the journey of hormone therapy.

> "I said OK I'll give myself two, three days to say, I'm free of treatment at the moment and then I'll start with it, yeah." Interview 8

Another woman, with the blessing of her GP, decided to wait until she had finished the chemotherapy before starting hormonal treatment.

> "I didn't start it when I was going to start it because my GP did say let's hold off for a while because you're still having your chemo. You don't want that as well." Interview 10

5.3.1.5 Necessity of the treatment

These women believed the treatment to be necessary; to them, taking the treatment was a small price to pay, taking into account its associated benefits.

> "So I just reckoned, again doing a cost benefit analysis, that it was worth taking the medication." Interview 4

Women start the treatment because they understand its importance and the fact that it decreases the chance of cancer recurrence. When asked about their main reason for taking the treatment, most replied on the lines of understanding the importance of the treatment and the fact that it was their best option of preventing cancer returning.

> "Because they said it was the best chance I had of it not coming back." Interview 6

> "Well the main reason that I decided to go through that is because they said that you reduce the risk of cancer coming back, so that was the main motivation to be honest to do it." Interview 8

> "I just thought, well yeah, I'll take it, because obviously I don't want to get the cancer back again." Interview 10

5.3.1.6 Fear and worries

Difficulties during the initial stage of the treatment affected how the participants perceived the medication. A participant was afraid of the nausea before starting hormonal therapy due to the fact that she suffered from it during the initial stage of the treatment. The same quote shows the effect of others' experience on the participant's perception of the treatment; she is talking about her friend's bad experience with the side-effects of hormonal therapy and how this made her anxious about starting her own medication.

> "Yes, I had one friend who had struggled with it because I had two friends I knew who were taking it and one had terrible nausea. And my problems, I had very,

very bad nausea during chemo and also, I had and in fact, ended up with sepsis during chemo as well and various other complications. So, I was anxious about taking it." Interview 9

"I wasn't fearful of doing it but I, in a very weak state because the chemotherapy affected me very, very badly; surgery and radiotherapy were a walk in the park." Interview 14

Fear of recurrence is clearly evident from many of the interviews. Having gone through the initial stage of the treatment, the women did not want to relive the same experience, deciding to take the treatment to make sure they would not have to go through it. When asked about the main reason for taking the treatment, one woman answered:

"Fear of cancer." Interview 9

Fear of death is also noticeable in many interviews. This participant considered the treatment her best option of staying alive; to her, the necessity of the treatment was associated above all with its ability to keep her alive and well for as long as possible.

"I didn't want to die. I didn't want to die just yet. And, yeah, I just didn't want to die just yet. I've got too much to do." Interview 11

Fear of the possible side-effects of the treatment is also to be observed in the data. Despite going ahead with the treatment, women still feared its long-term effects and what it might do to their bodies.

"And then they gave me all the instructions and what are the side-effects of this medicine and so on. So when I read all this I said, oh no what is coming?" Interview 8

"It's six years' ago. I think that I was anxious about how I would feel taking it. I was anxious about the side-effects." Interview 9

As suggested, this fear did not necessarily lead to a decision not to take the treatment; for many, side-effects were a small price to pay for the benefits the treatment could provide.

> "No, not really because I suppose I felt, well, I was told that there would be side-effects with the anastrozole, or possible side-effects, but for me, if the worries about a few side-effects and prolonging my life was, it's, it, that was, that was the benefit." Interview 11

One worry some women had at the prescription stage had to do with whether they were being prescribed the correct treatment. Another concern of some was a lack of certainty about whether or not they were menopausal, making them wonder whether they should be prescribed tamoxifen or an aromatase inhibitor.

> "I did have some concerns because it was a drug that had to be taken, you already have had to have gone through the menopause to have taken that as opposed to Tamoxifen and I was, well have I, haven't I, how do, you know, how do I, I was just borderline on that. Am I taking the right drug, so yeah, I did have some concerns yes." Interview 1

> "I don't know, because I, they told me no this isn't right, but I wasn't menopausal when I was diagnosed with the cancer and also I wasn't fully menopausal after chemotherapy, radiotherapy, taking Tamoxifen, so I obviously wasn't ready to have the menopause." Interview 5

> "I'd previously been told I would have letrozole, they said oh, we, I don't think we can do that, we'd better give you tamoxifen and I knew from looking at the literature that letrozole was a bit better." Interview 14

5.3.1.7 Vulnerability

An important aspect to cover at this stage is vulnerability. To some, becoming a patient and having to go through so many procedures and medications was a novel experience that made them feel vulnerable.

> "I did feel very vulnerable because I'd always been a very well person and I think people who haven't experienced a serious illness are perhaps not aware of how vulnerable you feel when you are diagnosed with something." Interview 2

> "I felt vulnerable having not been a patient before and having all these procedures." Interview 7

Another thing that made some women feel vulnerable was having to go through body changes while they were in the public eye. To some, enduring cancer was not a topic they wished to be visible to others.

> "Vulnerability I think is key, and I would say as an academic, somebody who appears in public, who considers herself to be a very capable person, going through that vulnerability is something, is one of the biggest life changes you have to deal with." Interview 4

Context: Completing the acute stage of treatment for breast cancer

The care of women being treated for breast cancer, in the UK guided by the National Institute for Health and Care Excellence (NICE), involves treating women with chemotherapy, radiotherapy, or surgery at the acute stage and with long-term treatment with a hormonal drug given as appropriate.

Trust in their healthcare provider

Causal conditions	Actions/interactions	Consequences
Transitioning into a new stage of breast cancer treatment Being overwhelmed by information provided all at once Fear of cancer recurrence Fear of possible side-effects of the new treatment Lack of specific information and uncertainty about the medication (*necessity, efficacy, safety, mechanism of action and type*) or lack of understanding of the provided information Feeling vulnerable The memory of difficult experiences during the initial stage of the treatment (*at a personal level, professional level or emotional level*)	Having a consultation about the medication where it is prescribed Accepting or deferring the treatment *(dependent on e.g. trusting their healthcare provider advice, awareness of the necessity of the medication, the level of stability in family and social life, emotional stability and support, desire to continue living cancer free, co-morbidities, need of normalcy)* Women taking care of themselves Women looking for information elsewhere (*through specialized websites, specialized forums or from other patients*)	Going along with the hormonal prescription Delaying the hormonal treatment Transitioning into the long-term treatment phase with ease (*trusting the treatment and finding the necessary support*) Having difficulties transitioning into the long-term treatment phase Being well informed by receiving the correct information (*not looking for information in the wrong places and correcting misconceptions about the treatment*) Being wrongly informed about the medication (*side-effects, mechanism of action, efficacy and safety*) Fewer hospital visits (*less communication with healthcare providers*) **Guided by the doctors: accepting the long-term prescription**

Worries and expectations

Knowledge about the treatment

Support from friends and family members

Figure 5-3: The paradigm model for the category 'Guided by the doctors: accepting the long-term prescription' (verified and corrected).

5.3.1.8 Modifications to the paradigm model for the category 'Guided by the doctors: accepting the long-term prescription'

The data from the interviews matches what was identified in Chapter 3. Some few additions to the model are shown above in Figure 5-3. In regard to the knowledge about the treatment, it is not only lack of information that is an issue. Sometimes the issue is the participant's understanding of the provided information. Health literacy levels are different from one woman to another, so what some participants find easy to understand, others might find confusing and difficult to comprehend.

> "Lack of information, or lack of understanding − and I think maybe that's a bit different. Because lack of information is one thing isn't it, because you can have as much information as you want but you can't, some, you just don't understand it." Interview 12

Another important piece of information identified in the interviews and added to the model above, is the fact that participants had concerns not only about the necessity, efficacy, safety and mechanism of action of the treatment, but also about the suitability of the treatment they were prescribed. As mentioned above, this mainly has to do with them not knowing for certain if they were menopausal or not when they started the prescription. Thus, the choice between tamoxifen and an aromatase inhibitor appeared to cause worries to some women.

> "I did have some concerns because it was a drug that had to be taken, you already have had to have gone through the menopause to have taken that as opposed to Tamoxifen and I was, well have I, haven't I, how do, you know, how do I, I was just borderline on that. Am I taking the right drug, so yeah, I did have some concerns yes." Interview 1

> "I don't know, because I, they told me no this isn't right, but I wasn't menopausal when I was diagnosed with the cancer and also I wasn't fully menopausal after chemotherapy, radiotherapy, taking Tamoxifen, so I obviously wasn't ready to have the menopause." Interview 5

Another mediating factor identified in the interviews was support from friends and family members during the prescription. The data show that women who had support from family members or friends had a much better experience than the ones who had to go through the experience alone. One woman talked about how helpful it was to have her husband with her at the prescription visit, specifically in that it helped her understand and remember the information they were told by the healthcare provider. Another participant mentioned how important having a friend with medical knowledge was in helping her process the situation better.

> "I'd obviously read it and then obviously I talked to people before I went to start, to have my appointment, my follow-up appointment, and I took somebody with me who knew about the various types of medication." Interview 1

> "Yes. I was quite lucky, that I think I had a lot of information, perhaps a bit too much maybe if anything but my husband went to all the appointments with me, so there was two of us to listen." Interview 2

> "I think the only thing I would like to add on the background differences, is the support. Because I think that makes a big difference and that support could be family or friends or, because there's an awful lot of people that go through this quite alone. And that must be just so dreadful when you're considering anything, any thought. So I think the support is a big, is quite a factor as well when you're considering any sort of treatment. Because you come away and you talk to people about it and the different people you talk to, if you haven't got that when you come out of the hospital after you've seen the consultant, you're on this therapy and you haven't got anybody to bounce ideas off or bounce side-effects off. I think that must be quite difficult and I know that the family support and friends support that I had just was amazing." Interview 12

As mentioned in Chapter 3, mediating factors identified in this study do not act separately, they act together and interfere with each other throughout the prescribing process, as shown in Figure 5-4 below.

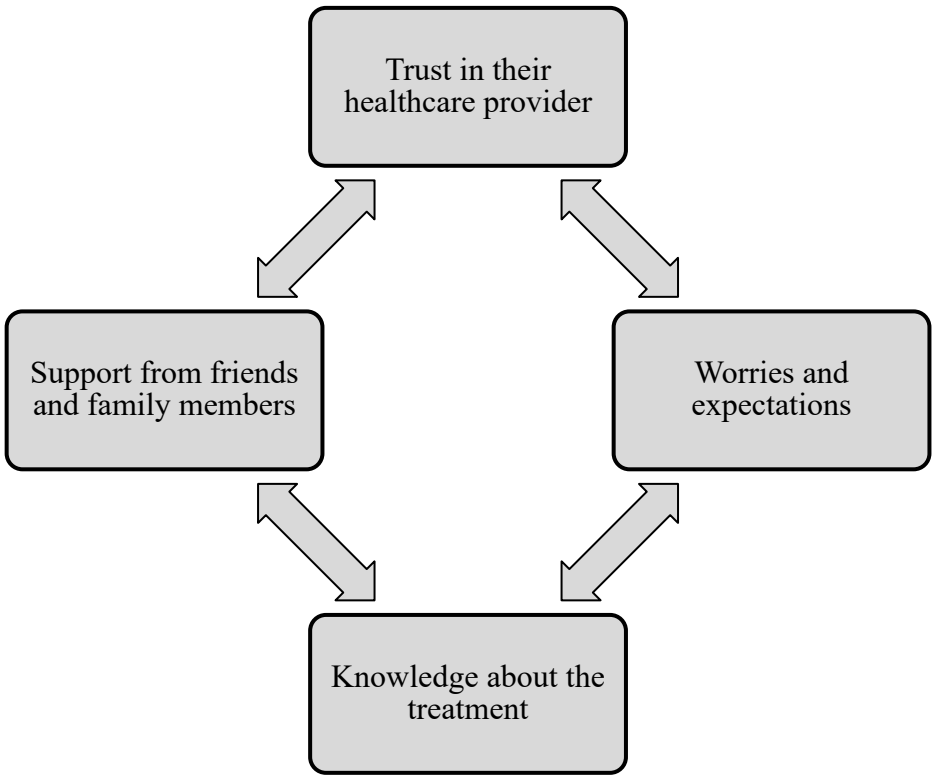


Figure 5-4: The relationship between the four mediating factors identified in the category 'The treatment of breast cancer: prescription of a long-term drug' (verified and corrected via the interview study).

5.3.2 Balancing priorities: adhering to the long-term treatment

5.3.2.1 Commitment

Women experience hormone therapy differently. Thus, in this section of the Results I capture the women's experiences while they were trying to adhere to the treatment, and I present the similarities and differences in their experiences. Generally, women in the study tried to adhere to the treatment as best they could. They were committed to the treatment plan.

> "I just thought, well no, I know it's helping me so I'm going to just keep going." Interview 5

> "Once somebody advises me that you have to go through that then I say, yeah OK, this is what I need to do so yeah." Interview 8

> "I think psychologically, it probably wouldn't have made any difference if I'd stopped a few months earlier, but psychologically I had set myself that goal, it was like getting to the top of Everest." Interview 14

A factor that plays an important role in participant commitment is the fear of recurrence. The data show a clear fear of cancer coming back, with some participants recognizing it as the driving force behind their decision in favour of taking the treatment. Participants wanted to continue living cancer free, leading them to look upon the treatment and its side-effects as a small price to pay for what the medication could potentially provide.

> "At that time you just don't want it to come back so you just think, well if I don't have the hormone for the cancer to feed on it's, the likelihood is it won't come back and I think that's the more, the forefront of your mind you just don't want the cancer to return so you take anything." Interview 3

> "Well, the main reason would be to prevent the hormone, because my cancer was hormone receptive, it's to prevent the cancer coming back." Interview 4

> "Because at the time − I don't know if it's changed now − but at the time there was no chemotherapy for my type of breast cancer. I was more worried that if it came back then maybe I'd be stuffed, for want of a better word. So I would rather put up with any minor side-effects and reduce that risk, so…" Interview 7

> "I still have this sense that anything to stop it coming back is worth it. And there are other side-effects that I also don't like but in comparison to a recurrence, you put up with it." Interview 9

Some women showed commitment to take the treatment as prescribed for their family's sake, feeling as if they owed it to them to adhere and to do all they could to prevent recurrence.

> "I have two kids, so yeah, initially when I was in the previous stage, considering whether I go through this treatment or not, then I will say, yeah, I had to do it for my kids, so yeah that happens." Interview 8

> "Because it's not just for yourself that you're taking these tablets, it's for your family." Interview 13

Although in some cases the side-effects were very severe, some women, showing great commitment, continued taking the treatment. One participant quoted here judged the trade-off to be well worth it and regarded suffering a few side-effects as nothing by comparison with what the treatment offers. Another participant who was suffering from very severe side-effects talked about experiencing them as confirmation that the treatment was working and doing what it was supposed to do.

> "So, yeah, the volcanic moments and the night sweats were a bit, a bit of a bugger, but better to put up with something that's a bit inconvenient and be alive than not, was my view." Interview 11

> "I did read some encouraging research that the more severe the symptoms the better the prognosis. I don't know how true that is, but I thought, oh, it's working." Interview 14

5.3.2.2 Trust in the treatment

Participants generally trusted that the treatment was their best option to prevent cancer recurrence and showed readiness to bear the side-effects no matter how severe they might get, due to their belief in the treatment's necessity.

> "I saw it as a positive thing because I, you knew they found a treatment that, I wouldn't have had to take it unless it was going to be beneficial and I was fortunate that I was hormone receptor positive to that sort of treatment." Interview 1

> "It was necessary to prolong my life. Otherwise if I hadn't had the treatment, I had a life-threatening illness." Interview 2

> "I have but it comes back to the fact it could prolong my life and the side-effects, hopefully, when I come off of it, will go." Interview 6

5.3.2.3 Perception of the treatment

Perception of undergoing the hormone therapy varied from one participant to the next. While some looked on it as an easier experience by comparison with what they had endured during the acute stage of the treatment, others took a different view, considering it an even less pleasant experience.

> "Yeah, so I think the surgery was really the big thing and also knowing that I'd need chemotherapy as well and then taking the Tamoxifen was a third thing, but it was of less, lesser significance to me at the time because I found the other two pieces of news quite upsetting." Interview 2

> "Yeah, yeah, it is really, because, all right the chemotherapy you lose your hair, but I was lucky, I didn't feel sick, I didn't have any side-effects other than obviously you get very tired towards the end, but for a lot of it I felt fine, yeah. Although you do start to have hot flushes with the chemotherapy because obviously it's knocking on the hormones isn't it, but not as much as with the Tamoxifen, because you can imagine having a hot flush every 20 minutes and they last quite a long time and it goes on for 24 hours a day, so it's not like it stops at night. It disturbs your sleep so for, since I've been on that, I always have disturbed sleep. I don't sleep soundly because you're having the hot flushes all the time, yeah. They have worn off but I, not completely, but assume that's to do with my age, so yeah." Interview 5

Participants' perception of the treatment was shown to be strongly side-effects-related. When asked if their perception had changed over the time of taking the treatment, their responses showed side-effects to be an influential factor, whether positive or negative:

> "Well, my perception slightly changed simply because I didn't see all the side-effects happen and I said, OK fine it's just an extra pill, so…" Interview 8

> "Well yes, because I didn't know that it was going to be, have the side-effects. They don't tell you the side-effects then, they tell you you've got to take it, they give you the leaflet but and my GP just prescribed it, she didn't talk to me about it." Interview 10

Some participants talked about the fact that they still felt themselves to be a 'patient' while taking hormone therapy. Despite being cancer free, taking the hormone therapy pill every day served as a constant reminder of what they had to endure.

> "I do feel I'm in remission and the longer it goes on the better really, but I, once you've been a cancer sufferer, you're always a cancer sufferer in your mind." Interview 2

> "From, well obviously I'm only six months on this thing, but still I feel like, even if I had, I had my surgery and all this stuff, I had radiotherapy, I started hormone treatment but I still felt sick. So yeah." Interview 8

> "Well yeah when I take it every morning it does remind me that I've had breast cancer, yeah. So yeah it does, it does remind you." Interview 10

Another participant actually contradicted this and thought the treatment and taking a pill every day was not a big deal, feeling that because she was already taking medications daily, one more pill was not a problem.

> "So every morning I'm taking Thyroxine so it was just an extra pill so I took 75mg so I had one more. So it didn't change much of my routine to be honest, instead of two I was taking three so I said, fine. So that's why I didn't find it hard to start taking a pill every day." Interview 8

5.3.2.4 Support from family, friends and co-workers

Support from family and friends was felt to be important during the treatment, helping participants cope better with the experience.

> "My friends are very good and very supportive. I have a very close friend who works in the Intensive Care and she has been my rock really." Interview 6

> "I mentioned family but my friends were just completely amazing." Interview 10

> "I just don't tell him often enough, they, they've been there when I've wanted them to be and friends have done that as well. They've, friends from a long time ago have come back into my life because they thought I needed them." Interview 12

However, not everyone could count on total support from these sources, other participants mentioning the inability of some friends and family to offer help and support. Reasons referred to included people being busy with their own lives and issues, and in other cases an inability to deal with the cancer diagnosis.

> "Some of them couldn't cope with it as well as others, because some people have their own, one of my quite close friends she couldn't cope with it because her daughter had gone through leukaemia when she was about 12 and she couldn't, she couldn't cope with supporting me because it just brought it all back, which I completely understood." Interview 10

> "Some friends I've lost completely because they couldn't cope with it." Interview 12

> "They couldn't do this and they couldn't come and live with me to look after, I didn't needed looking after I needed nursing but they couldn't give up their lives, their work, their, looking after their families and people who are ill in their own families." Interview 14

Some participants mentioned how helpful they found it to have a friend who had survived breast cancer and gone through a similar journey to their own. To them, having someone who understood what they were going through, and with whom they were able to talk to freely and openly, felt "great". Having someone close to them who was able to offer advice from their own experience gave these participants a feeling of security, making them better able to cope with the treatment and its side-effects.

> "When I was going through cancer, a friend of mine, who'd also been through it, was, her advice and help was enormously helpful to me. So I would say that the support of other people, who've been through what you're going through, is enormously useful." Interview 4

> "I was so lucky when I went through my breast cancer because I had a friend who is sadly going through, who had already gone through and sadly she had mest so she didn't make it but I was so fortunate to have that, someone to hold my hand and talk back, quite openly talk to her about whatever I felt and I just, I know how that made me feel. It made me feel so much more secure and able to cope that I just felt that you want to give back really." Interview 13

One participant talked about the importance of empathy. For her, despite her family and friends not being able to provide her with the physical support she needed, the empathy and understanding they offered was enough to make her feel better. Another participant talked about how some people displayed a lack of empathy toward taking hormone therapy. She felt that the issues women experience while on hormone therapy are poorly known, with the fact that they (the participants) appear normal on the outside, making some people dismiss what they are going through.

> "That was the support I, I had the empathy of my friends and family." Interview 14

> "I don't think the hormone therapy is very publicized, people laugh at hot flushes, but they can be really, my sleep pattern at night is dreadful − it's off, on, off, on and you're tired, I feel tired. I think when you physically look different people

> feel sorry for you when you've got no hair and your face is all bloated because of the steroids and they're, oh, but then when you start looking better I think people soon forget." Interview 3

When asked about the support received from family members, one participant talked about the fact that offering support was *her* role as a mother. Similarly, another participant mentioned that she did not feel comfortable taking about cancer with her family, because protection and support are "part of being a mum and a wife". To these participants, motherhood took precedence over breast cancer and their need for support.

> "Yeah, and also my, I had, my daughter had a very serious problem with her eyes and I think when you've had children, you really worry about them, and when, and I had many sleepless nights pacing the floor with adrenalin with her, when I had my cancer diagnosis I didn't even lose a night's sleep with it, so I think it's having kids. Also my children would have been able to look, they were older, they weren't babies, so I think that made me, and also it's just my nature. I'm just somebody that's going to roll with it if you like, so yeah." Interview 5

> "But sometimes it's not easy to talk to family because you, naturally, you want to protect them. So, that's what you do. That's part of being a mum and a wife isn't it? So, yeah." Interview 6

Fear of being a burden on their close ones was another factor reported by one participant as the reason she felt unable to ask her family and friends for help. She preferred to deal with cancer on her own rather than trouble someone else with her issues.

> "Yeah, I am and I have this concept that, it's my problem so I have to deal with it. I shouldn't burden other people. All through my cancer, the only way I could deal with it was, every time they told me something, we used to say, put it in the jam jar and screw on the lid, and that's where it stays. Because, I knew my family couldn't cope with it and it's not fair to burden other people, so, yeah, no, I don't look for support." Interview 6

Support at work was an important factor reported as easing some participants' experience on the treatment, although here again support levels varied. While one participant here recalls about how supportive and understanding her employers were, another talks about the fact that some women might find it difficult to discuss their diagnosis with their employer for fear of losing their job.

> "Also, I would have to say that my, my work colleagues were supportive and HR worked very carefully with me. So I was able, during that time, to do flexible working and that was enormously helpful." Interview 4

> "Yeah and some people worry about losing their job if they tell their employers." Interview 14

5.3.2.5 Support groups

The experience with support groups was different from one participant to another. Some women liked being involved with support groups while others did not. One participant talked about how helpful it felt to share things with women who were going through a similar experience. Another mentioned meeting another breast cancer survivor at the support group and then becoming very close friends, helping each other throughout the treatment.

> "Yeah well it does help to know that other people feel like they're 90 when they get up as well, not just me. [Laughter.] I think we all discuss how horrible it is." Interview 10

> "I am in touch with the breast support group that she runs and I went to it before I started chemotherapy and met somebody that I kept in contact with that I found, she'd been through things and so we're quite friendly now, we don't see each other quite so often but we keep in touch." Interview 12

Others, when asked about support groups, were quite reluctant to speak. One participant said that attending such groups and sharing her experiences with others was simply not in her makeup. Another went to a support group once but felt out of place as all the other

women there knew each other. A third participant went to a support group but found going to the meetings difficult and that even when she went, they were not able to offer the help she needed due to the severity of her side-effects.

> "To be honest I'm not, it's not in my character to go in these groups and start sharing my experience so far. I don't like it anyway so that's why I didn't try to get involved a bit further." Interview 8

> "I went to one and I thought that would be good, but they all knew each other very well and they were all of, they were all a bit older than me and they were of a different age. And they weren't, they were very nice people but they weren't professional people." Interview 9

> "I did eventually join a Breast Care Support group, but they don't really, well if, be well enough to get there for a start, but there were no support groups specifically for this." Interview 14

One participant shared that she did not know about the availability of support groups and thought that information should have been provided to her when she was prescribed the medication.

> "No, I haven't. I wouldn't even know where to go to actually look for one. That may be something that would be good to be introduced in the early stages of when you are actually prescribed this medication." Interview 6

One participant who worked at a support group shared her experience in the interview, speaking about the help she was able to provide by answering survivors' worries and putting their minds at ease and how fulfilling she found the experience of providing others with help, support and guidance.

> "I'm on a helpline so sometimes I do get ladies ringing me and suggesting that the, asking about the side-effects and was it normal, etc., because you tend to, sometimes when people have side-effects they're not necessarily clarified. Well,

they're not mentioned actually when you're prescribed and sometimes people don't read the leaflet they get inside and even if they do they sometimes think that the symptoms that they're getting have got something to do with the cancer so get quite nervous about it. When someone does ring and they do have a problem and at the end of the phone call they say, oh, thank you so much, I feel so much better now. And I think to myself, well, actually I haven't really done much at all but to hear that it's so nice to know that you have been able to relieve their stress a little bit because it's a big problem, the stress levels, yeah." Interview 13

5.3.2.6 Relationship with healthcare provider

Having a good relationship with healthcare providers was reported by some participants as a factor that improved their experience. One woman talked about how meeting the same healthcare provider at every visit helped her greatly. She felt that her healthcare provider was able to notice any changes, whether positive or negative, and address them accordingly. Another participant talked about establishing rapport and how being comfortable enough to share small talk with her healthcare provider helped her greatly.

"It did throughout the treatment, because she noticed any difference in me, so if she thought I looked worse or looked better she was able to see that, so it was, it was quite good that she was at my last appointment as well. I know it doesn't, it doesn't always happen because when I went back after a year she wasn't there, she'd left, but certainly for me it worked really well that it was the same person." Interview 12

"I used to like going in and talking to him. He liked motorbikes. I liked motorbikes. So we used to spend, he'd go, are you OK, and I'd go, yeah I think I'm fine, he went, right OK let me just check. He'd check and then go, and then we'd spend 20 minutes talking about motorbikes. I had a very good relationship with him. You know, in that respect, I loved him. And I also loved him because, as far as I was concerned, he saved my life." Interview 11

Other women reported a different kind of experience. One participant met with a different nurse every time she went for a visit and felt that it was almost impossible to establish

rapport and build a relationship. Another participant when asked about her relationship with her healthcare provider replied “non-existent”, feeling that healthcare providers thought of her as just a number.

> “Yeah, I think it is because you don’t, they say when you first get diagnosed that you’ve got your healthcare nurse, the breast cancer nurse but you never see them, it’s always someone else that you see so then you don’t really build a rapport up with anybody, that was my experience.” Interview 3

> “No, yeah, non-existent. It, I felt a bit like a machine. OK, and next number please. Yeah, I don’t, I don’t think there was a relationship.” Interview 6

Women reported the importance of trusting their healthcare providers. One woman talked about how, having faith in her healthcare providers helped her try and adhere to their advice as best as she could. One participant talked about not actually having a choice in the matter: she felt obliged to trust them because, as she put it, her life was in their hands.

> “I had total faith in the guys that were treating me, so if they said to me, that’s what you need, that’s what I was going to do, yeah.” Interview 5

> “I trusted my two consultants all the time, because I thought if you don't trust them then it’s just important to know that, feel as though they're doing the right thing.” Interview 10

> “I think you have no choice. If someone’s got your life effectively in their hands, you have to trust them.” Interview 11

One participant talked about losing trust in her GP, feeling that they were dismissive of her experience and lacked the understanding and knowledge to deal with her situation.

> “I certainly lost trust in my GP as a consequence of how, they basically, you, they basically at a time I suppose you’re under hospital care but when you’re, there’s ongoing that you’re under the GP care as well. I felt really that I wasn’t supported

by the GP, particularly when I had concerns and then they dismissed them and then I had to go back to the hospital then to find out I could then have a bone density scan, so I lost confidence in my GP throughout, because they had little contact with me." Interview 1

Some participants shared their worries about healthcare providers' overprescribing. One talked about how her healthcare provider had been ready to prescribe her a medication she was already taking and feared that had she not notified him she might have ended up being overdosed. Another woman shared her worries that healthcare providers are linked to drug companies and that their prescription patterns are related to that fact relationship − a thought she called "cynical" but nevertheless couldn't shake.

"I went to the doctor for something and he was going to prescribe some ibuprofen type tablet and I said, do you know that I'm meant to be taking ibuprofen anyway? He said, 'Oh no I didn't know that, oh no that won't be any good for you then.' So, you just think, actually they don't even read your notes, they don't even know what you're taking because they would have overdosed me on that, wouldn't they?" Interview 3

"One of the things I worry about is whether oncologists, I don't know this, but whether the oncologists are linked in with certain drug companies. So that's something I wonder about and whether, in some cases, they're recommending treatment that doesn't always have to be prescribed." Interview 4

5.3.2.7 Professional Support

One of the difficulties reported by participants at this stage is the bureaucracy in the healthcare system in the UK and the different hoops they had to go through to ask for tests, medications or to just meet a specialist. The ability to deal with this complicated process again differed from one participant to another and played a role in the service received. One participant talked about her complicated experience of working around the bureaucratic complications to ask for a bone density scan and the many steps and hoops she had to jump through to finally be able to do it. Another participant shared her experience of feeling lost when she had to deal with a blood clot and how, when her GP

told her to go to the hospital for the prescription, she felt lost in this bureaucratic labyrinth and ended up thinking, “just give me the medication”. Another participant shared her preference for the [another country – removed to maintain anonymity] medical system with which she was familiar. There, she said, she could more easily find the healthcare provider she needed, rather than having to go through the complicated UK bureaucratic process of booking an appointment with a GP in the hope of being referred to a specialist.

> “I spoke to my GP about it and having a bone density scan, and they told me that I wasn’t entitled to have one. I was concerned for two reasons. One that, well I’d had a few joint pains and aches and pains but then I thought that was, that could have been anything at my age whatever, but also because I’d had radiotherapy and I knew it was, well the risk factors with taking the treatment and it wasn’t, so I, she went through various criteria, told me I wasn’t entitled, and I went back and spoke to them in the hospital. My consultant wrote a letter and then I had a letter from the GP saying yes they’d arrange for me to have a bone density scan, and then I found that I’d osteopenia and so they prescribed alendronic acid for that.” Interview 1

> “I had a blood clot in my arm because your veins started to collapse and I had to have this injections for so many months after, it was a bit like, to thin the blood and then they kept saying, oh well really the hospital should be prescribing these because of the budget, and you just think, well I don’t really mind just give me the medication. So, I think there’s a little bit, the oncology, the doctors.” Interview 3

> “Yeah it would be something that I would really love to have when I have an issue, can I see the oncologist, obviously the NHS doesn't work like this. You have to go through several steps in order to reach the specialized doctor. In “their country” as well it's like this. You go to the doctor that you want, whenever you want, whenever you feel that you want to see it rather than waiting to get an appointment whenever, yeah. OK.” Interview 8

This brings the issue of cooperation and communication between the different health sectors into question. Some participants shared their experience with their GP and the fact that they showed no interest in interfering with a hormone therapy prescription. Even in the case of side-effect-related issues, GPs were reluctant to offer advice and guidance and suggest that the woman should contact the oncology team that had prescribed the medication.

> "It's hard to get an appointment at the doctors anyway and as I say, I don't really feel as if they're that interested in this. They just say, oh yeah well the oncology prescribe them so, no one's ever reviewed it." Interview 3

> "I tried to talk about it to my, one of the doctors at the practice, the one who takes my blood because he's the best one, but he wasn't, he just thought I should talk to the oncologist about it." Interview 9

Healthcare providers' limited knowledge of the treatment was mentioned by some participants. One talked about GPs' lack of knowledge and training in dealing with a breast cancer diagnosis, mentioning the need to provide them with the education that would enable them to it handle it better. Another woman talked about her side-effects and the fact that her healthcare providers were unable to provide her with the help she needed. She thought that they simply did not know how to handle her condition.

> "Nowadays you get a 12-month follow-up following your treatment. So it means that the GP is the person that is dealing with the hormone treatment and unfortunately they really don't have the information that they need to deal with. So again it's about education, it's about GP education. I mean if you talk to a GP, I do go to various conferences and lectures and what have you, and if you talk to the GPs they really do feel that you're having a go at them all the time. And that's not what we're saying. We're just saying that the powers that be need to make sure that GPs, I don't know how you do it because they do have access to the information, but they just don't do it." Interview 13

> “I don’t think they, I don't think it crossed their minds, I don’t think they were withholding information from me, I don't think they, I don’t think they knew it.” Interview 14

The same participant raised the question of the necessity of doing more research, especially since from her own experience, healthcare providers’ knowledge about the side-effects and how to manage them was clearly lacking.

> “Why isn't there more research into the side-effects when they're crippling?” Interview 14

Healthcare providers tend to be busy. To some participants, finding an appointment proved rather difficult, and the issue came up multiple times in the interviews.

> “It’s hard to get an appointment at the doctors anyway.” Interview 3

> “I don’t really routinely because they are just so busy, aren’t they?” Interview 7

One of the complaints about healthcare providers was their occasional lack of compassion. Two participants mentioned how healthcare providers sometimes showed little or no compassion, and how condescending their actions could sometimes be. One of them highlighted how such behaviour could prove positively dangerous.

> “They're so used to giving out the medication, they don't really think of it, of the side-effects of it, I don’t, I just don’t think they realize how horrible it is to take.” Interview 10

> “A lot of GPs do not know, if you go in with a lump, even going with a lump if you’re a young woman they will suggest it’s to do with your cycle, your menstrual cycle, and will not take it seriously, OK? And women know their body. He’ll say come back next month. See how you go with it in a month and come back. Well, if you’ve got a young woman who’s got an aggressive breast cancer, that’s actually too late and I have, I’ve had ladies who have joined our support group

> who have died as a result of the doctors not taking their fears seriously and not referring them." Interview 13

Another participant talked about a friend of hers who was going through a similar journey and the fact that, when her friend contacted healthcare providers to ask for information, she was really looking for hope and encouragement rather than knowledge.

> "She's contacted Harley Street, because her way of dealing with it is she just wants more and more information. Basically she wants to be told if it's going to come back or not and nobody can tell her that." Interview 10

While compassion is important, one participant talked about how a sympathetic healthcare provider was actually less helpful to her. From her own experience, she found practical healthcare providers were the ones able to provide her with better care.

> "Whereas I think those who were sometimes overly sympathetic or something, it actually didn't really help." Interview 9

One participant talked about the fact that she was assigned a breast cancer nurse to help her throughout the treatment and answer any worries she might have; however, she was not informed of her availability or how to contact her. Another woman shared her experience of not knowing that cancer nurses could have offered her help with hormone therapy-related issues.

> "Well, the one thing that wasn't helpful, that didn't help me, was you were assigned a breast care nurse and I didn't really make use of it because I thought I don't have one. So, I think that was the one thing that it hadn't been clear to me that I could contact her." Interview 9

> "I haven't to be honest, because you do go back to your cancer nurse once a year for the first five years, so my last one was last year and then they do say that if you have any problems to come back and to contact them, but I think that's more

> if you find any lumps, that's what I assumed − I didn't think it was related to the hormone therapy." Interview 3

Not having enough hospital visits or access to healthcare providers was reported by some participants as a factor hindering their experience. One talked about how having too few hospital visits made her question her treatment. Another shared her experience of how vulnerable it made her feel.

> "I suppose with less hospital visits and less contact with professionals you begin to question things a bit more, including any medication you're on." Interview 1

> "Yes, that was I think because I didn't have a care worker, in a sense, or didn't make use of, I hadn't quite realized that I could, I think therefore I, there were fewer hospital visits, so it was yeah quite interesting, big difference. I think I possibly felt more vulnerable, probably." Interview 9

Treatment follow-up is usually on an annual basis. Participants talked about how 12 months is a long time without seeing an oncologist. Another participant talked about the fact that even during the follow-up visit, medication was not discussed at all.

> "Whilst I was on the treatment I was having, obviously I was having annual check-ups and mammograms, so if I had any concerns I could have spoken about it then. It was more a case of more of a physical examination and I was asked if I had any concerns, but they didn't specifically mention my medication. It was actually just, it was almost forgotten about, really." Interview 1

> "I don't think so, no. I don't think it's changed at all. I think I thought I would have more one-to-one consultations with oncologists in the beginning, rather than six months gap, and then a 12 months gap. Where 12 months is a long time." Interview 6

Another issue in regard to follow-up visits is their duration. Participants talked about how short these sessions were and the fact that, as a result, they did not have enough time to discuss their issues with their healthcare providers.

> "I think the problem in this country as well now is that GPs are so stretched that they don't have time to sit down with people to discuss things like this, you know." Interview 7

> "And so that would have helped, but I, mostly in general practice there isn't the time for that kind of discussion, usually." Interview 14

Some participants talked about the importance of keeping a journal to record all their breast cancer-related issues. Writing everything down helped them remember their experience and proved helpful when they wanted to share them with their healthcare providers during their follow-up visits.

> "Because this is my little book you see, so all the way right from the beginning I wrote everything down, because I thought I can't, you can't remember." Interview 10

> "Yeah and I think that's what I would say to people as well, is to write everything down, how you're feeling, keep a diary so that when the doctor says to you, 'And how are you?', you don't say I'm fine, you can say 'actually I'm OK now but two weeks ago I was feeling really sick'." Interview 12

Participants expressed their need for more professional support during the treatment. They talked about their need for someone to talk to who could answer their worries and help them navigate their experience. Sometimes the need for professional support is not just physical or related to issues with the treatment, as emerged when one participant talked about her need for support to ease her state of mind.

> "Yeah, I think so, even if it's just a nurse. It doesn't have to be the doctor, it's just someone to say, 'How are you getting on? What are your side-effects like?'." Interview 3

> "I don't think it's anybody's fault, the doctors and the oncologists, they have to see so many people that there probably isn't the time, and, I guess, maybe my case wasn't as severe as many others, so, though other people needed their time more than I did, but, mentally, I think I needed the time. Maybe not physically, but mentally." Interview 6

> "So, well, the support I needed was something to take the edge off the worst symptoms, to make them manageable and that really is from people like yourself and medicine and specialist nurses I think, really." Interview 14

One participant reported her inability to ask for help, feeling that picking up the phone and contacting someone to ask for information and guidance was not part of her nature. She also spoke about her fear of becoming a burden on the healthcare system was she to do so, fearing that by contacting her healthcare providers she might be taking time from someone whose need might be greater.

> "Some people would find it very easy to just ring up their breast cancer nurses and say, 'Oh, this is happening, that's happening, what do I do, is this correct, is that correct?' But there are other people, that that is extremely difficult, and one of those people is me. And then you feel like, you're taking the appointment of somebody else that may be desperately need to see the doctor, whereas I'm just asking information. I feel like I'm taking their time up when there's probably someone else that needs them more than I do." Interview 6

When asked about future visits, participants shared their experience of how these were usually booked in advance. One participant talked about how her hospital called her to arrange the follow-up visit. Another had a different experience as she usually had her appointments booked and confirmed before leaving the hospital at her previous appointment.

> “Yes, they will contact me, yeah, yeah. Because my timetable is so busy I usually call them months in advance to set up my meetings. But if I don’t do that, they will call me.” Interview 4

> “That I always had the next letter for the next appointment. I was never at home worrying about not being seen and that makes absolutely so much difference.” Interview 5

The pharmacist’s role in the healthcare system was obscure to most participants, their experience being that pharmacists usually just deal with minor illnesses and dispense prescriptions. However, one participant talked about how her pharmacist offered her advice when she went to them with a side-effect of hormone therapy, and how that advice helped her.

> “Yeah and they see pharmacists more as a, you know, to discuss minor ailments with really, rather than maybe their prescription medication.” Interview 7

> “What one of the pharmacists told me, this was in the, not in the hospital but in the, because I didn’t meet, well apart from when I went to collect the initial drug I didn't meet, well it wouldn't have even been the pharmacist then I saw. One of them I asked about the headaches and he said that although a lot of people will say, with something like ibuprofen it doesn’t matter which brand you take, actually it does, because of the excipients in there and that, and then I started looking up, I did look up that information as well, that although you're always taught, no, no all these other things they're just packaging, they don't affect the patient − oh yes they can, and actually they can interfere with the action of some, I think is it particularly cardiovascular? Sometimes they can interfere with, so I started looking up all of that. And he said no, take; he recommended for the ibuprofen, the Nurofen, rather than the cheaper brands, and actually I did find a difference between the brands.” Interview 14

5.3.2.8 Knowledge

Knowledge and information about the medication and its side-effects play an important role throughout the duration of the treatment. Some participants expressed a need for more information.

> "I would like a bit more information really, because of this gap there is in terms of the long-term implications of the treatment and whether I should be taking it or whether I shouldn't." Interview 2

> "I wished it had been explained a little bit more, with the side-effects of them. What to expect and also, whether there was any other options of drugs that I could have taken." Interview 6

Some of the women were always looking out for the latest information in the field. Asked about their main source of information, their answers varied. While some referenced their healthcare providers, others mentioned google, specialized websites and friends as their main sources of knowledge.

> "I suppose it was the internet, really, and obviously talking to, if I wanted to I could have spoken to a professional. I did consult with somebody who is a pharmacist, but more as a friend." Interview 1

> "It would be my GP now. Obviously, when I was under the hospital, which was for the first five years, then it would have been my consultant at the hospital." Interview 2

> "I have to say, I did do quite a lot of research online. I'm a researcher, although I'm in arts and humanities, but I did do a lot of online research." Interview 4

> "I went to Doctor Google. And then having at times, if I'd read too much nonsense on Google, I then got in touch with either Macmillan or Breast Cancer Now." Interview 11

While the internet proved useful to most women, others talked of the dangers of seeking information online, due to the fact that much of the information they were able to find came from women who were experiencing difficulties with the treatment, which some of the participants found alarming.

> "You have to be a bit careful though, because it can be a little bit frightening. So, I think you have to pick and choose the information that you actually take from that, very carefully, but yeah, but, a lot of the time, I try not to think about it." Interview 6

> "I think for somebody who's a medical professional, I think yes, because you can weed out the incorrect information, but I think for somebody who isn't, I think it could be a big problem that they can find incorrect information on the internet or things that might scare them." Interview 7

> "I Googled things and I knew what to ignore and what I thought was good. So I, you Google things and all these things come up and all these chatlines come up with everything, people, with all the negatives, because no one goes on a chatline and says how good it is, it's always what goes wrong. So I learnt to ignore most of that and go onto Cancer Research or Breast Cancer Now sites and look at the information there." Interview 12

However, some women talked about their experience of visiting specialized websites rather than forums and how this helped them find the information they were looking for or guided them to other possible sources of information and contacts.

> "I went to breast cancer, there is a website breast cancer and then there is another one, the Macmillan one." Interview 8

> "If I'd read too much nonsense on Google, I then got in touch with either Macmillan or Breast Cancer Now. I'd ring them up and ask them." Interview 11

> "I learnt to ignore most of that and go on to Cancer Research or Breast Cancer Now sites and look at the information there." Interview 12

One participant reported that despite having access to the information she needed online, she was not told by her healthcare provider where or how to find it. She felt that this responsibility lay with the medical team and that they should have explained it better.

> "I had access to information, if I needed it I knew where to look, but I didn't feel that was offered. I often had to ask for it or look for it." Interview 1

Another participant talked about how lost she felt, not knowing who to ask or reach out to when in need of information. She felt that everything was rushed initially and that, once she had begun the treatment, primary healthcare providers were reluctant to discuss a medication they had not prescribed, leaving her feeling abandoned.

> "I didn't really know who to ask because as I say, the oncology team are quite rushed, and you've gone through your treatment, so you just feel as if they're giving you them and then my doctors aren't really that helpful with it because they've not really prescribed it. So, I think you're in a bit of no man's land in a little way where the hospital, the oncologist is dealing with life and death not hormone treatment and your doctor's thinking, well actually I haven't prescribed that, that's the hospitals, so yeah you are a little bit out on your own, I think, with them." Interview 3

Differences between participants and their need for knowledge emerged from the interviews. Some were keen to have information in advance to help them deal with issues should they arise. Others preferred not to know about possible issues until they encountered them, fearing that if they knew in advance, for example about the drawbacks of hormone therapy, they might worry more and allow their 'imagination to run wild'. One participant shared that she found herself experiencing both these scenarios during different phases of her treatment.

> "I prefer to know, yes, and I find it reassuring to know." Interview 2

> "I think the trouble with telling me about side-effects is I might find I have them where if I know that I could have them, if that makes sense." Interview 12

> "Not always. Because the more you know, the more worried you are, to be honest." Interview 8

> "I go through different phases of that." Interview 4

One participant talked about the necessity of knowing what side-effects she might encounter, and how best to cope with them. She mentioned the need to stay positive, but in a realistic manner: to her, positivity and realism needed to go hand in hand.

> "Yes and also the positivity in a realistic sort of way, because I've spoken to people since and there's people going through chemo it's all right saying it was fine, but it's not fine, so taking letrozole I, if people ask me about letrozole and tamoxifen I'll say it's fine, but I have had problems with different brands and I do get quite stiff in the morning, but if I walk it gets much better; so it's knowing the negatives but also working out how to make that better, not just knowing the negatives. So I think being informed about what could happen but what could make it better, yeah, is good." Interview 12

5.3.2.9 Side-effects of the treatment

The side-effects of hormone therapy treatment are one of the most important factors associated with taking the medication. The participants in this study experienced side-effects very individually, some reporting minimal to no side-effects, others moderate to severe. Those suffering minimal side-effects described a better experience with the treatment.

> "It was fine actually, I didn't have any side-effects." Interview 1

> "I would say that the side-effects have not been so drastic that it has massively affected my quality of life. I would say that, also having taken it now for four years, I would say that I'm less aware of the side-effects." Interview 4

> "I think when I started I didn't know how bad the hot flushes would be and they haven't been as bad as I know, I have a good friend who's really had horrendous hot flushes with Tamoxifen and had to come off it in the end. So I think from that point of view I was quite pleased that it was maybe not as bad as I thought." Interview 7

> "No side-effects really. Not something that I noticed for example, something that changed in my routine, no." Interview 8

By contrast, the participants who reported moderate to severe side-effects described a worse experience on the treatment.

> "Yes, I don't like taking them to be honest. My hair was thinning, my nails were really weak, and the joint pains and you read all the side-effects and I do think, you do get the side-effects. I just feel as if I'm being pushed into old age before it's my time, that's how I feel." Interview 3

> "I've experienced quite a few side-effects from the drug, which some days, I really struggle with, so, I've put on quite a bit of weight since I've been on it and I get a lot of pain in my joints." Interview 6

The reported side-effects were both physical and psychological in nature. The physical effects mentioned by participants included hot flushes, headaches, muscle pain, joint pain, lack of energy, drowsiness, blurred vision, dry mouth, vaginal problems (dryness, soreness and continuous infections), nausea, weight gain, fluid retention, thinning hair, weak nails and impaired memory. The psychological side-effects reported by some participants included anxiety, negative body image and insomnia.

> “I would say that at first I felt, I definitely had some side-effects, and I’d say that those probably continue. The main thing I would say is anxiety levels, I think, obviously there’s a bit of hair thinning, all those kind of things. So, I don’t enjoy taking it.” Interview 4

> “So, the hot flushes I’ve had quite, I say not badly, they, they’re a pain. Lots of musculoskeletal tightness. I don’t sleep very well. Memory, I’m sure it’s made my memory a lot worse. I have vaginal soreness.” Interview 7

> “The worst one of all was very severe headache, crippling, so I could barely move. What comes with the headache is, can't concentrate, can't think, can’t function, barely function. I had, feeling sick and that, that I can deal with. Balance, I have a bit of vertigo, but the loss of balance was bad and I fell twice at home because of it; nobody did anything about that, I reported it. Muscle pain and pain. Feeling, just no energy, very severe urine infections, very severe. I had some of the others, swelling and things like that. Oh with the headache the most awful irritability, as if there was wire wool inside my skull, and that was exhausting, not to really have a go, and it wasn’t related to anything that was happening to me. It was really, really bad. Blurred vision, I have dry eye syndrome anyway, so that got worse. Dry mouth, that didn't trouble me, I could put up with that. More of arthritis. Very thirsty. Vaginal infections. Just feeling very weak, very weak and very difficult to function and plan anything, very difficult. Feeling sick, not often being sick, weight gain, I didn’t mind about that. Fluid retention, joint pain, muscle pain. All of that I could put up with but it was the headache and very sleepy. Couldn’t stay awake sometimes and tired. It’s very difficult to, even doing nice things, it’s very hard to do that.” Interview 14

The severity of the side-effects could reach the level of being disabling, some participants reporting difficulty in carrying out their normal daily activities.

> “I took the tamoxifen, I think about a year, but unfortunately I had just about every symptom on the list. It was just awful. In fact I had double vision, I had terrible sickness, all, I mean all sorts of things. In fact so much so they actually

> gave me a brain scan because they thought maybe it had metastasized into my brain. So, yeah. So obviously following the spec when I, once I'd, they'd done me the brain scan and they'd realized it wasn't they realized it was the tamoxifen." Interview 13

> "I've had viral encephalitis in the past, very badly, and it wasn't diagnosed at the time so I was ill for a long time, and the headache from that is, well it's as if your skull has shrunk. And I would put the headache from, that I had from letrozole, not as severe as that but in the same class. That's like a slight movement of the head is just and sometimes all I could do was just lie completely still." Interview 14

I asked the participants whether the side-effects were as they had expected or if they came as a surprise. Although some said they were as expected, others shared their shock about how severe some of the side-effects proved. In some cases, even if the woman knew in advance about the side-effect in question, its severity came as a complete surprise to them.

> "No, because I'd read very clearly the instructions, so I was expecting them." Interview 9

> "I am surprised by that tiny little white tablet, what it can do to your joints and, people laugh at hot flushes, but they can be really, my sleep pattern at night is dreadful − it's off, on, off, on, and you're tired, I feel tired." Interview 3

> "I was surprised at how, you know, volcanic they were where all of a sudden you're sort of, I don't know, kind of sat minding your own business and then all of a sudden you get this rush of fire coming up through your body and frazzling your head." Interview 11

A side-effect of the treatment mentioned by one participant was the effect hormone therapy can have on intimate relations with a partner or significant other – an issue the woman described as "quite a challenge".

> "I suppose if you think what an impact it does have, it does have an impact on everything. Even my, with my husband, the intimacy with my husband it's affected that. You don't really talk about it because you just think, oh well, but we're still quite young and to be going through it now it's quite a challenge really, yeah." Interview 3

Women reported difficulties with the body changes caused by the treatment and with having to adapt to looking different. Weight gain was reported multiple times as a source of distress, another factor being the effect hormone therapy can have on hair colour and thickness. These changes were described as "difficult" and "depressing".

> "Oh yes, because I looked completely different. I still look different. I have grey hair, I had brown hair before, I lost my hair and it's come back grey. So I looked completely different. So it's finding yourself as well, so I think that's not typically, not really the hormone treatment, but you're taking hormone treatment when you look different from the other treatments and that's quite difficult." Interview 12

> "My hair has changed completely and that's my, that's the thing that depresses me most or upsets me most. So, and it's like baby hair now and it's so thin compared to, I had a lot of very thick hair which came back after chemo but the anastrozole has definitely affected my hair." Interview 9

Another issue reported was the loss of control while on the treatment. One participant talked about how the treatment pushed her into premature menopause. The sudden transition from being a healthy young woman into someone suffering from menopause-like symptoms was difficult to comprehend and adapt to.

> "Obviously, you go through the menopause, you're getting all the signs of being menopausal at quite an early age and no one really explains all of those properly to you, I don't think, because you just stop bleeding and then that's it. So, you haven't gradually, it hasn't gradually happened, so all of a, you've got none of

that. So, the hair, the dry skin, vaginal dryness, all of that comes in and you're just like, woah I didn't expect all this. So, it's quite a sudden transition from being a healthy 48-year-old to feeling that you haven't got much control anymore." Interview 3

One of the disturbing consequences of the treatment is the effect it can have on memory. Multiple participants used the term "chemo brain". However, from the participants' point of view, the matter is not always straightforward. Participants questioned whether the effect on their memory was attributable to their chemotherapy, their hormone treatment, or simply to getting older. One participant, asked about whether she ever forgot to take the treatment, identified the stress that goes with the treatment and continues after finishing it, as the reason behind her memory worsening.

"I'd also say that definitely, I can't hold things in my head the way I used to. Now I don't know whether that's chemo brain, but it's four years since I had chemo. I don't know whether it's age, I'm already in my sixties, or whether it has something to do with the medication, but definitely I would say I am forgetting things." Interview 4

"I also think that I don't know whether it's chemotherapy, I don't know what it is, with what I've been through, I don't know if it's the letrozole, but my mind certainly can't take in as many things and work on all of them at once." Interview 12

"Oh God, yes. [Laughter.] You've seen what my memory's like and I'm 17 years on. During, I mean they talk about chemo brain, which maybe if you've spoken to other ladies it's come up once or twice. I didn't do chemo but I really had a problem with chemo brain after my treatment and they suggested that it's not actually necessarily the drugs. The reason why people like me, who didn't do chemo, still have trouble with it is that in fact it's the stress level. The stress of being diagnosed, the stress of waiting to have your treatment, the stress of doing your treatment, the stress of everything that goes with that. And then afterwards you would expect, well, that's all that stress gone away, you've not got cancer

any more, and the stress then of wondering will it come back. So that basically is where the, where the, where it all comes from." Interview 13

Participants mentioned their desire to feel like their usual selves again and regain the sense of normalcy in their lives. One participant talked about the fact that she was looking forward to stopping the treatment, because taking a pill every day was a constant reminder that she suffered from cancer, and about how this feeling acted as a barrier preventing her from feeling normal. Another woman spoke of her desire to return to her old self, before the cancer diagnosis, and to go back to work as though nothing had happened; a third talked about her desperation to find a way to manage her side-effects, just to be able to live "something of a normal life", as she described it.

"There is that sort of psychological effect where when you stop, when you do stop, and I'm talking about at the very end stage when you stop taking it, you do feel OK, so you can sort of, you're obviously starting to normality that you're no longer, you associate taking medication with something wrong with you, so it's like progress" Interview 1

"What I do think, and I think this is really, really important, is that I did, I wanted to go back to work as soon as possible. I thought that I could just take up my life as if nothing had happened, and that is not the case." Interview 4

"Because I thought that if there was information about what caused it then maybe might be able to look or reduce it to manageable levels, I wasn't so naïve that I thought they're going to be able to take away all these effects, but maybe I can go on living something of a normal life. Maybe I have to reduce activities or, but maybe I can feel more human than I do at the moment." Interview 14

Despite their wanting to feel normal again, going back to work was emphasized by some women as being a difficult step to take. One participant mentioned returning to work for financial reasons, talking about trying to go back as though nothing had happened and how she now thought this a mistake she should have avoided, but due to financial constraints and previous work commitments had felt forced into. Another woman talked

about having to go back to work, despite feeling really sick, due to her commitments to others and a feeling of needing something else to occupy her.

> "It had just taken so much of a toll in every way, physically, emotionally, psychologically, that looking back on it I think I probably should have done a phased return to work. But of course, there were financial implications, because you can take six months on full pay, and then after that it's half pay, and I have a mortgage to pay. And that was partly why I did the flexible working, so that that could go against the sick leave period. When you have PhD students, the support you give to them, you can't measure that in hours, actually. And also we're quite a small department and I'm in film, theatre and television, and I'm on the theatre side, which is quite small, quite a young team. So I see mentoring responsibilities as being quite important there, plus, of course, my own research. So it's very difficult for that not to take up all your time, and that's something I'm working with, is that idea of really trying to pull back." Interview 4

> "I had a PhD student and I thought, I was very positive the whole time, it was just reflecting back I think, oh gosh. It's strange but I kept working even though I was really sick in the morning. I would, when I was at home, I would make sure that I was dressed, and I would get to my desk by about 11. I just needed to have something else to think about and so and even when I was in hospital, so I was admitted twice." Interview 9

Some interviewees' felt that the treatment and its side-effects had a negative influence on their social life. One woman talked about how, since being on hormone therapy, drinking caffeinated beverages or alcoholic drinks had caused her to immediately experience a hot flush. Another participant talked about the fact that since beginning the treatment, and due to its side-effects, she had tended to be more bad-tempered.

> "As I say, my health, and even to the stage where if you go out for a drink now, I'm always thinking, shall I have coffee with caffeine or an alcoholic drink, because that just gives you a flush immediately." Interview 3

> "Definitely, yeah. And, sometimes it can make you grumpy, if you're, if my joints hurt for a few days, it gets on top of you." Interview 6

But here again, not everyone reported the same experience. One participant shared how the treatment had influenced her social activities at the start, but no longer did to the same extent. Other participants, who experienced minimal side-effects from the treatment, said that it did not affect their social lives at all.

> "It did for a while, it doesn't so much now but it did for a while, but we live in a quite isolated place, so we don't have a huge social life." Interview 9

> "I don't think, because I didn't have many side-effects." Interview 2

> "No, I wouldn't say that, it's done, it's particularly done that. I'm not, I'm not off to parties every evening." Interview 4

Participants report their difficulty in distinguishing whether the side-effects they felt were hormone treatment-related or caused by other treatments or simply getting older. Hormone treatment is long-term, so eventually perceptions about side-effects tend to become entangled with other things, some participants saying they found it difficult to know what was causing what.

> "Well I'd had a few joint pains and aches and pains but then I thought that was, that could have been anything at my age whatever." Interview 1

> "I have, I say lots of musculoskeletal tightness, the problem is you have these symptoms and you don't know whether they are due to the drug or if you would be like that anyway." Interview 7

> "You know, it's difficult isn't it, because you kind of think, well, if I'd not taken the anastrozole, would I have had them or would that be my menopausal journey, was that, you know…" Interview 11

The side-effects of hormone therapy were not the only concern participants shared about their medical treatment. Another was a fear of side-effects from other treatments taken to manage those side-effects. One participant expressed concern about co-codamol, an analgesic she was taking daily. Another participant, prescribed an anti-inflammatory medication to take daily, reported that due to her fear of the long-term implications of that medication, she had decided to reject the prescription.

> "To take co-codamol every night, surely that's not that good because when they tell you, the pharmacist always says, oh you shouldn't be taking it for more than three days or so, and you think, well actually they prescribe it to me to take every night." Interview 3

> "So I then went to the GP and the GP then said if I took anti-inflammatories for ten, for five years. Well, I read *The Lancet*, same as he does, so I told him that and said, no, I don't think so, thank you very much indeed. I really don't want to do that because the statistics on anti-inflammatories are people die, 5,000 people a year die taking them long term. And so my choice is do I die of cancer, do I die of taking anti-inflammatories? I'll take my chance with the Arimidex, quite honestly." Interview 13

5.3.2.10 Side-effect management

Participants talked about side-effects management and techniques they implemented to make their experience better. Side-effects management is a big part of living with a hormone treatment. One of the mentioned ways of managing the treatment's side-effects was to take other medications.

> "They put me on Venlafaxine, which they said is an antidepressant, but they found that it helps with hot flushes. My concern was that I'm somebody that's quite happy naturally, and I didn't want to take something that, when I came off it, might make me feel different, when normally I'm a happy person − yeah, even with cancer I'm a happy person. They said no, you don't need to worry because it's quite a low dose, so I went on 75mgs and it certainly didn't eradicate the hot flushes, they were still debilitating, but I carried on with that. Then I decided I'd

> come off it because I wasn't sure that it was really helping, and then when I did come off it I realized that actually the hot flushes were even worse without it, so it had; although it didn't get rid of them and they were still severe, it was even worse if I didn't take it." Interview 5

Hormone therapy can negatively affect bone density and lead to the development of osteoporosis. Some participants talked about having to monitoring their bone density throughout the treatment and having to take alendronic acid to improve their bone health.

> "My consultant wrote a letter and then I had a letter from the GP saying, yes, they'd arrange for me to have a bone density scan. And then I found that I'd osteopenia and so they prescribed alendronic acid for that, so I was taking that at the same time as taking the Arimidex, yeah." Interview 1

> "I should also say, because this is part of the whole pharmaceutical package that I'm on, I also have osteoporosis. So that is a side-effect of Anastrozole, which I'm on. So I also have to take alendronic acid, which is an awful nuisance. But I can see that, I've had a couple of bone scans since then, and the bone density is increasing." Interview 4

One of the lifestyle modifications mentioned by some participants was either working fewer hours or quitting work completely.

> "I went part-time, at work. So, that's what I mean when I say I made lifestyle adjustments." Interview 4

> "Well I've given up work, which is, I took early retirement because I was off and then realized my job was quite stressful and family became more important than working all hours." Interview 12

Some participants talked about wearing multiple layers to counter their sudden hot flushes; this way they could adjust what they wore by taking a layer or two off when the felt a hot flush coming on and put them back on when they started to feel cold. One

participant talked about her use of humour as a coping mechanism if experiencing such an episode when with friends or colleagues.

> "Yes, I, where, I was always a cold person and then when I was on that I couldn't wear anything that, for warmth, because as soon as I put on something that I would have worn before [Nonverbal sound] hot? Yeah, so yes, I had to change the way I dress dramatically, yeah. Then of course when I had the hot flushes with the Tamoxifen, that was just more of a humorous thing because I was always taking, it was a joke. Because they, I think although I had a serious cancer, because of the way I coped with it, people, they forgot really quickly that I'd even had it. If you, that's what it was like, yeah." Interview 5

Diet and exercise are a common method of adaption and something multiple participants talked about. One participant reported giving up smoking, another deciding to drink less alcohol and cut down on red meat.

> "I've kind of thought about my diet a bit more. I gave up smoking. I suppose that my adaptions were wearing lighter clothes, because I felt hot all the time. I don't wear tights anymore. I very rarely wear woolly jumpers, even in the winter, so those are the adaptions I've made to it, but I try and see it as a, actually it's had a benefit because it costs me less money heating the house." Interview 11

> "The other thing I would do is that I, I don't do a lot of exercise, but I do a lot of stretching exercises and I walk, so I'm trying to do more exercise. So more exercise, less alcohol, I try to watch what I eat so that we eat more healthily, I've cut down on red meat, that kind of thing, and green tea or other herb teas and turmeric. That's probably about it." Interview 4

One participant talked about Pilates as a useful exercise for countering joint pain and stiffness, another about walking being a helpful technique to reduce joint stiffness.

> "I do Pilates every day, every morning and that really helps with knees because I have aches in my knees sometimes." Interview 9

> "Yes, I think it would. I think knowing that if you've got joint stiffness, it's quite painful, so the fact that you go for a walk might not be the first thing on your mind, because the first thing on your mind would be sit down and have a cup of tea. But actually a walk, walking does help it and exercise helps and I'm not very good at that, but it does, so…" Interview 12

Meditation and yoga were also mentioned by one participant as useful techniques for reducing stress and improving overall health.

> "Yeah, I do meditation, mindfulness, yeah, so yoga, meditation tapes where you just hear and they tell you how to relax and things like that." Interview 3

One of the techniques mentioned by participants as a way of countering side-effects was taking the treatment at night rather than in the morning.

> "So yes, so I started taking them, had side-effects, especially the sickness side of them, and the breast cancer nurse just said to take them at night or just to change when I took them, so I take them at night now instead of in the morning and to be honest, the side-effects have worn off, the sickness side but the hot flushes haven't but that's another, yes." Interview 3

> "Yeah, and it's possibly because I could take them at night but then I prefer, I just think I'm fine with taking them at night and I'd rather not have that in the daytime, so yeah." Interview 9

However, this did not work for everyone. One participant shared her experience of taking the treatment at night and how it affected her sleep to such a degree that she had decided to go back to her previous routine of taking it in the morning.

> "I did think, I think we were on holiday actually, and I thought oh I, I'd spoken to somebody and they said they took it at night, so I thought I'll, why don't I take it at night because then if I'm sleeping I might not notice the aches, but then I

couldn’t sleep because of it, I ached so much in the night, whereas I think during the day, because I have to keep going I don’t notice. So then I went back to take it in the morning again, so…” Interview 10

Some participants experimented with various alternative treatments for the management of their side-effects.

“I’d have to say I take green tea, I take turmeric, but, and I think those things are useful, but I’m not sure that they actually outweigh the benefits of pharmaceutical medication.” Interview 4

“My day job if you like is natural health products and I took an aloe vera-based drink with glucosamine and chondroitin and MSM in it, and to be honest with you, within two weeks I was like a new woman, it was amazing because I’d been suffering with really bad shoulder pain, knees, ankles. I couldn’t get up off the floor it was so painful, and no strength. So, and once I’d taken, started to take this product, I actually, I was, two weeks and I was, as I say I was like a new woman, it was amazing.” Interview 13

“I went to this medical herbalist who was recommended, she has a good reputation in Oxford. What she gave me eased the headache and improved my concentration, it still wasn’t any, wasn’t good, but and she gave me for the vaginal issue, she gave me, because all the other creams and stuff they helped a bit, she gave me comfrey oil – fantastic, and the vaginal infections cleared. The urinary infections I had very, far fewer of them, to the extent that my GP wanted to know what herbs were, oh can you tell me, I have women coming who can't, and so for me that made it a little more bearable.” Interview 14

However, some participants showed reluctance to use treatments of this kind, fearing their possible side-effects.

“I wouldn’t have considered taking any sort of alternative medicine because I knew there may be reasons why you shouldn’t do that.” Interview 1

> "No, because I considered sort of like the herbal things, like red clover and black cohosh, and there's so many bad reports of liver failure and all this sort of thing, I thought it's just not worth it." Interview 7

> "I thought about it briefly and then I haven't. And I don't know why I haven't because I know alternative treatments do work for some people, but I'm living my life as I did before, really." Interview 12

Changing the treatment from one hormonal medication to another was not uncommon. Some women were advised to change their medication by their healthcare providers. Some decided to change it by themselves, either to escape the side-effects of the treatment or owing to a preference for one treatment over another.

> "The reason he, he showed statistics, it was a different consultant and he queried why I was on tamoxifen so I explained and he showed me the statistics to say that the chance of reoccurrence was less at my age, so post-menopausal, if I took letrozole. He said tamoxifen worked better with pre-menopausal ladies, so what he did was, he showed me the statistics and looking at it, even though it was a very small percentage, that meant I would have less chance of reoccurrence that, even if it's 1 in a 1,000 better, that, to me, that was worth changing the tablets. So and he also put me on some calcium and vitamin D for my bones, so that took away the worry of osteoporosis as well, so…" Interview 12

> "I took the tamoxifen I think about a year but unfortunately I had just about every symptom on the list. It was just awful. In fact I had double vision, I had terrible sickness, all, I mean all sorts of things. In fact so much so they actually gave me a brain scan because they thought maybe it had metastasized into my brain. So, yeah. So obviously following the spec when I, once I'd, they'd done me the brain scan and they'd realized it wasn't, they realized it was the tamoxifen, they actually did prescribe with the Arimidex." Interview 13

> "I got the prescription for the tamoxifen but I investigated myself the possibility of transferring to letrozole." Interview 14

Some women decided to stay on the treatment rather than change it, fearing that doing so might affect them negatively and cause them to experience other side-effects.

> "Even though potentially I could have less hot flushes, anyway. So, in a way it was sort of a blessing in disguise that I would prefer to stay on the Tamoxifen than change to something that I wasn't really sure about." Interview 7

One of the techniques mentioned by participants to counter the side-effects of the treatment is to change the brand of the medication. The reported experience shows a clear difference in some cases where participants report having a better experience on one brand of the treatment than the other. The idea of changing the brand of the treatment in mentioned by one participant as something that is not usually discussed in the consultation visit.

> "Although I don't know if the other, anybody else has said this, there are different types, there are different manufacturers of these tablets and with one manufacturer it, I had very, I had really stiff muscles, bones, my ankles were really sore and I've found that if I stick to certain manufacturers of letrozole I am much better. So if I, I now put on my prescription, I do not want this brand of letrozole and I don't know. Yeah I have told somebody else this as well, her elderly mother took some and she asked for a different type as well and since the side-effects seem less. So I don't, it's just one of these things, it might just be, I don't know, no but it definitely, yeah." Interview 12

> "I do obviously know but there are different generic, there are different manufacturers and they're not necessarily exactly the same and so my suggestion if they're having problems would generally be if you feel that you want to give up, first of all I would reassure them that it's not normal whatever it is they're doing, that they're getting if it is, and then I would suggest that if they suggest they don't want to come off it, they want to come off it I will obviously tell them

about the benefits of it. But also I will say to them to go back to their GP or their consultant depending on which stage they're at to actually suggest that they perhaps take a different type because I've had quite a few people that have gone from one to another and found that one suits them so much better. So that's not something, again that's not something that's usually mentioned during a consultation. So it's quite important really." Interview 13

However, not everyone shared a similar thought process. One participant wondered if the idea of changing the brand of the treatment and having a more positive experience on one brand than the other is something that is just 'in patients heads'. She thought that as long as both have the same amount of the active ingredient trying a different brand would not actually make a difference.

"I mean I did do a search once and it had women saying that they, their, and in fact, I think Breast Cancer Care don't pooh-pooh this, but it depended on the brand of Tamoxifen they were having, depending on how their symptoms were and you're thinking, well either that brand isn't worth, it's not by available or, it's all in their head, so it's things like that you sort of think, well I don't, unless that brand's not giving you the amount of Tamoxifen it should be, then it's, it's obviously not going to make any difference." Interview 7

In an attempt to manage the side-effects of the treatment one participant talked about her experience with a severe headache throughout the duration of the treatment. Due to the severity and after exhausting all standard solutions she tried to identify the reasons and mechanism of action of the side-effect to try and counter it by contacting the manufacturing company of the medication. She was told that the mechanism of action that causes the severe headache was unknown to the company.

"The other thing I did do was I phoned the company that makes letrozole, is it Fem, well that's a trade name isn't it, anyway that company. Because they had a customer helpline and I said, I'm wondering if you know what the mechanism is for causing the headache and the person on the end of the lien said, oh we're not allowed to give out that kind of information and she wasn't rude, she was a bit

abrupt but I think she was out of her depth. I think she just didn't know how to handle the and I'm on the other end of the line thinking, please don't speak like that because I am very irritable and I am really struggling not to shout at you down the phone, I'm really struggling to be really polite and I feel as if I've got something clawing inside my head. And no, no we're not allowed to give out that kind of information. Why? Oh no, no, we're not allowed to. And then I said, oh I think she said something along the lines of, it might upset people or it might, I, she didn't know what to say basically and then I said, well I am a healthcare professional, I think I can deal with the information and she said, are you a doctor, I said no, I'm a nurse, oh. Well I'll see if I can put you through to somebody else. And actually I think somebody phoned me back, who did know all about it, was involved in the actual production of the medication and she said, I'm sorry we don't know." Participant 14

One participant, describing herself as a "glass half full" person, decided to see the positives in the side-effects she was experiencing, thinking of her hot flushes as a way of saving on heating bills in winter. This determination to use optimism and banish pessimism was one way of dealing with her side-effects.

"But the benefit of the anastrozole was that I was no longer cold. I'm a hot, hot totty now. I'm a hot bird. So, the benefits for me is it doesn't cost me as much in heating the house, even in the winter, because I'm hot, whereas prior to the menopause, I was a, I always felt cold, so I'd have the heating on, I'd have jumpers on. Now, I'm just too hot. So my quilt, for example, whether it's winter or summer, is 1.5 tog and I'm still too hot with that at times, especially in the summer. Whereas before, I'd be tucked up under a 15-tog quilt feeling cold. So, for me, in a funny sort of way, it's been a bonus. I've saved money." Interview 11

5.3.2.11 Adherence

Participants shared how they would usually try their best to adhere to the treatment as prescribed, making the treatment part of their daily routine to make sure they never forget

to take it. One participant shared her experience with pill boxes and how she found them a helpful aid in adhering to the treatment.

> "I very rarely miss it, and I take it at the same time every day. So I take it with breakfast, and that works." Interview 4

> "Well I take blood pressure tablets as well, so every morning when I'm in bed I have a glass of water at the side of my bed and before I do anything I take my two blood pressure tablets and my anastrozole, first thing in the morning." Interview 10

> "I bought myself a Monday to Friday pill box and I'd put all the pills in it on a Sunday. So, it ran out on a Sunday and then I'd refill it for the rest of the week and then it was kind of like on my kitchen side near the kettle. So the first thing I went to in the morning would be the kettle, and next to the kettle was my pill box, so I've got no excuse not to, no to forget." Interview 11

When asked whether they ever forgot taking their medication, most replied negatively. The only time participants reported doing so was when a change occurred in their daily routine. So things like waking up late, having a meeting earlier than usual, or being on the move, were reported as reasons some forgot to take the treatment.

> "But I always take the Anastrozole with my breakfast, so I rarely forget actually. It has happened, I only forget really if my routine is completely out of kilter. In those cases, if there's something I have to deal with in the morning and things are not quite, or I'm up later than usual, it's something that, those cases I might forget, but I adhere very strictly, I'd say." Interview 4

> "To be honest, it doesn't, I just, it's just routine, it's now routine. I have it in a medicine box, I think I've forgotten it maybe in the past two years, three or four times, but it literally is because I've gone away for a night and forgotten my tablets or, it's not that I don't want to take it it's just that it slipped my mind." Interview 12

Asked how they felt about forgetting to take the treatment, participants generally did not worry and didn't consider missing it the odd time to be a big deal or something they needed to worry about. One participant did share how forgetting to take the medication made her feel "anxious" in the early days of the treatment, but added that she would not worry about it so much now.

> "Oh, it's happened so rarely. I reckon after four years of taking the thing, if I forget it's not going to make that much of a difference really, so I don't bother. I've never forgotten to take it for a week or something, you know, so…" Interview 4

> "Well first time I did it, I thought, oh my goodness, I need to, what do I do? And then I realized that actually, they're quite strong, so I didn't want to take it when I got home at night and then take another one in the morning, so I just missed a dose. And I just think that if you're taking tablets long term and one dose gets missed, then your body soon adapts to the next dose, and I just, I didn't, I don't think I even looked it up. I think just common sense said to me, look don't panic, this is long term, you take it every day, one tablet is not going to affect you too much." Interview 12

> "Yeah, I was anxious, I was really anxious. But it was a long time ago, and I would be less anxious now." Interview 9

Participants revealed a range of views on the topic of drug holidays. When asked whether they had thought of taking one, some participants talked about how terrifying the idea seemed to them, fearing recurrence so much that the idea hardly struck them as an attractive option.

> "I would be too frightened that something might happen in that period that I wasn't taking it." Interview 6

> “No. No, I'd be too scared in case the oestrogen came back and caused a problem. No, no, I just take it religiously.” Interview 10

But not everyone shared this view. Some participants talked about their interest in pursuing the idea of a drug holiday and their desire to discuss it with their healthcare provider. One participant talked about how some of women from her support group had taken a short break from the treatment on their own initiative. Another talked about her experience of taking a break from the treatment in the hope of countering some of the hormone therapy’s side-effects, before deciding to go back on it after a month had passed without signs of improvement.

> “I also would be quite interested to talk to him about taking a break, for example maybe taking three months off it to see what, how I feel, whether that makes any difference.” Interview 4

> “I’ve had ladies in the group that have been through the group that have done that and simply really themselves they’ve said, look, I can’t take this anymore, I’m just going to come off it − and then they’ve gone back on it again.” Interview 13

> “I did come off it for a month, I think that was to see whether my stiffness improved, but it didn’t seem to make any difference, but then whether a month was long enough I don’t know.” Interview 7

One of the things participants spoke of in relation to hormone therapy adherence was the fear some had of regret and of having no one but themselves to blame was their cancer to return. Their anticipation of regret was a driving force making some participants more adherent.

> “No statistics tell me that this is doing the best it can for me. And I just think I would never forgive myself if I took a break and my cancer came back, I would be convinced it was my own fault. Whereas this way if it comes back I've done the best I can.” Interview 12

One thing participants were understandably keen to learn was whether or not their treatment was working, not least because a positive answer to the question could provide added motivation to keep taking it and accommodate any side-effects. One participant talked about how, when she did her annual blood test for hypothyroidism, the results showed that her oestrogen level could not be measured, convincing her that the treatment was working and doing what it was supposed to do. She believed this test should be offered to all breast cancer survivors on hormone therapy treatment in order to ease their minds and improve their experience.

> "I think part of me thinks how do I know they're working, that's the only query I have. If somebody could give me a blood test and just say no, you haven't got any of those hormones in your body, I think I would feel quite reassured, do you know what I mean? It's kind of, you take these tablets, it doesn't seem to affect me very much, so what is it doing?" Interview 12

> "The other thing that kept me going was, I have thyroxin, which is prescribed privately because I was never followed up in general practice. And when my blood's tested annually, they do a hormone assay as well, and I could see that they couldn't measure the oestrogen, it wasn't measurable, and I thought, well, the letrozole's working. I thought, well I'm not going through this hell for nothing. I know that it is blocking the oestrogen because they can't even measure it and it's below the normal; maybe there are very refined tests that they could do, but with the normal ones it was below. This is because I, when they, at the clinic where I get the thyroxin from the blood test automatically that you pay for, checks all of them, so I had that information. I think actually, if I hadn't been having that, it would have been very useful to be, have been offered that, to at least know whether it was doing something I think really." Interview 14

One reason participants gave for not adhering to the treatment was having other priorities. When asked if she would ever consider not taking the treatment, one participant shared that she would actually stop if she decided to have another child. She thought having another child would prove a higher priority than her treatment, driving her to discontinue it.

> "Yes, if I was about to have another child. But if not, then no, I don't think so. I normally comply with what they tell me to do, to be honest, because other people they have more evidence on how to treat stuff, so I say, OK fine, I'm not an expert in this area so I follow instructions." Interview 8

The experience of having the prescription dispensed differed from one participant to another. One of the issues mentioned in regard to obtaining the medication was having to do it on a monthly basis. This was found to be frustrating, leading some participants to question why they could not be given it in longer-duration batches. One participant mentioned the effect being limited to a one-month supply had on her adherence level, as she missed some doses of her treatment due to running out of the medication.

> "I did have some problems initially with the regularity of prescription. It's, you could only have a month at a time, and I knew I was going to be on this treatment long-term, so why could I not have six months' worth and if I was going away on holiday just trying to get enough to cover. You had to plan ahead to get, make sure you had enough prescription to cover and things like that." Interview 1

> "The thing that is a nuisance is actually having to pick it up every month from the pharmacy, although it's not that far away, and timing that to the, when the next batch starts. So I've sometimes, again very rarely, lost a day or something between the starting of one in there." Interview 4

One participant talked about her experience of obtaining the prescription monthly and how she agreed with her doctor to change to having a two-month supply instead. She also talked about how taking this step helped her adhere better and think less about the medication and cancer.

> "The other thing was the doctor initially said that she only wanted me to have a month's supply, but I just, in the end I said to her, I'm on this for seven years, do I really have to apply every month? So I now get two months' supply of tablets, which works better. A month, I was continually running out, the month goes by

> quickly, so again I would, unless I'd have asked, I would be going every month. So again, I just think people should know that you can get two months' supply of it, because it saves you thinking about it all the time. To have to think about your tablets every month just brings it back to your mind doesn't it?" Interview 12

Participants ordered their prescription online then went to the pharmacy either the same day, or a day or two later, to collect it. This usually went like clockwork, with no issues. However, some participants talked about instances when the pharmacy did not have their prescription in stock and needed to order it from elsewhere. One participant talked about having to change her pharmacy because her original one continually had this issue.

> "I'd go in and find my prescription hadn't been sent through by the GP, and I'd have to go and collect it, or I'd have to come back on another day because they didn't have it. I actually changed the pharmacy and once I changed the pharmacy it became, they didn't seem to have as many issues as the original pharmacy did, so I stuck with them." Interview 1

> "Well, there has been occasions where there have been shortages of supply, not serious, but sometimes they have to give me a few pills and they get the rest in, one or two days later." Interview 2

One participant talked about her pharmacy providing the service of sending text reminders prompting her to fill in the prescription.

> "Yeah, well, Boots just text me. Yeah, they do my resupply so, yeah. You just opt to do that." Interview 7

5.3.2.12 Payment

Having to pay for the treatment is an issue with worldwide resonance, as previously discussed. When asked about this, participants showed sympathy and were thankful for not having to pay for the treatment in the UK.

> "I'd hate it if I'd had to pay for it. Yeah, I'd have to, but it's expensive. Thank goodness that I, that we have got the NHS." Interview 5

> "Obviously most places it isn't, no. I understand that. Oh, I would think so. Some people just couldn't afford to do it." Interview 13

When asked whether they were told about their medication being free of charge, participants' experiences varied. One mentioned being told about it in advance.

> "I was told it was free because they gave me an exemption card almost straight away actually, which I felt very blessed in having that." Interview 6

However, some participants were not told their medication was free and found out later by themselves. One participant had to pay for a couple of months before finding out about the process of applying for free medication.

> "Yeah, I didn't know that I could get this as, I didn't, I thought I had to pay for my prescriptions initially and that wasn't, nobody told me that I could have them free. I found that out later but it was quite soon afterwards, but initially I wasn't told that." Interview 1

> "No, I paid for it, just for a couple of months, until somebody said you have to fill in this form. In this country, if you fill in a form, cancer drugs are free, but they don't tell you that. My oncologist didn't tell me that. I had to find, I was told by somebody else, then filled in the form and got my cancer drugs free, but they don't tell you." Interview 4

One participant reported her experience with health insurance. She talked about the support her health insurance company provided her throughout the treatment and how cooperative they were when she needed to do further tests and examinations.

> "Yeah, well I'd have to say I was in the Irish system, Republic of Ireland, before I moved here, and private health insurance is normal. My husband is American,

again private insurance is the norm. So when I came, started back here, and I'd been a student here actually − but anyway, when I came back in 2011, I took out BUPA health insurance, so I had private insurance. And I have to say the treatment was brilliant. So the GP, I would say, is my main go-to person for anxieties and that kind of thing. But BUPA, but if I need any further support, BUPA has always provided that." Interview 4

5.3.2.13 Cancer and society

According to one participant with expertise, cultural differences play a "huge" part in breast cancer, women from different cultures dealing with cancer differently.

> "Yeah, of course, yeah. And also you've got cultural differences as well which we find, that's one of the problems in the UK is that people from ethnic backgrounds quite often they won't talk to anybody about, well, about breast cancer anyway and then, and certainly not been given information about being able to help themselves. Yeah, huge." Interview 13

How cancer is depicted in a society was another factor discussed in the interviews. One participant made clear her preference for keeping her own cancer diagnosis a secret, while another talked about how cancer is still a taboo topic, meaning that talking about it with strangers could be considered difficult for some survivors.

> "The only thing I was, the only time is, you're having it, that's fine, you're getting on with it, then you lose your hair and then you know that everyone knows you've got it, and that's, I'd rather people didn't know. Not because I'm embarrassed, but just because I didn't need them to know. Do you know what I'm saying?" Interview 5

> "And some people still fear cancer. The taboo's being broken down but there is still, I don't know if there is in your country, but here there still is a taboo about, a bit of a taboo about cancer, not as much as it used to be." Interview 14

5.3.2.14 The end of the treatment

Participants are prescribed hormone therapy for five years and told that at the end of that time they would need to come back to have their prognosis reassessed and discuss whether they would benefit from extending the treatment for a further five.

> "So, they said at the beginning, five years. When I went back, they've said that the history, new evidence has shown that patients that stay on it for ten years is more successful with the cancer not returning. So, I think they, for the price I think they just keep you on it for the ten years, and I assume you just stop after ten years." Interview 3

> "As to whether I need to stay on it any longer or whether they'll terminate it after five years." Interview 6

Participants' reaction to the prospect of being on the treatment for ten years rather than five years varied. Some were happy to continue as long as it made a difference and reduced the chances of any recurrence. Others were more reluctant, either accepting reluctantly or refusing to continue. Some of those who had not yet reached that stage of the treatment expressed a desire to terminate the process.

> "Now if they can prove to me that, that won't make any difference, I would probably go along with it because statistics say, whereas if they say there's another drug that I can take for the rest of my life that would stop cancer coming back, I would probably take that as well if, because it's a thing you don't want." Interview 12

> "Some of them can't wait to get off it, but most people, I have to say that most people, when they were told that they could take it for ten years, they chose to do that. They got to the end of their five and they were, right, OK, well, then I'll, that's the end of it or if they'd perhaps for whatever reason they'd said, no, I'll go for ten." Interview 13

> "Oh, once I got to the end, my last, yes, because then there was new research out and what they wanted me to do was take it for another two years and I just said 'no'." Interview 14

> "As to whether I need to stay on it any longer or whether they'll terminate it after five years. I'd like it to be terminated." Interview 6

The experience of reaching the end of the treatment also differed from one participant to another. While some participants were happy to reach the end of the line and quite excited to stop the treatment, others were worried that stopping the treatment would mean losing its protective properties.

> "Relieved. I just hope that it hasn't damaged my joints and that when you stop taking them, that the pain and everything will go and the hormone still might kick in and I might get nicer hair, and things that I had before might come back." Interview 3

> "Yeah, they told me, yeah. If they'd have said to me, you've got to be on it on the rest of your life, even though obviously it gives me the hot flushes, I still would have done that, yeah." Interview 5

> "Well, I just think if you stop taking it after ten years, how do you not know, that's what worries me, because I think if then the oestrogen's produced, I don't understand why you don't take it for life." Interview 10

> "No I don't think so, I think, I go by advice really. It will be scary coming off tablets, but equally it'll be quite nice not having to take them." Interview 12

When given the choice to stop, some participants decided to stay on the treatment. One participant mentioned being given the option to stop by her healthcare provider after finishing the five-year course, but decided to continue treatment for an extra two, eventually stopping after seven years on the treatment, more than the recommended duration at the time. Another participant was still taking the treatment 16 years after her

initial prescription. This is quite similar to another participant, who, as seen below took a similar decision.

> "I was asked after five years if I could, if I would like to come off it, but we are very nervous as ladies when we've had breast cancer and I elected to stay on it for a couple more years, even though I did have some side-effects." Interview 13

> "They didn't tell me at the time and I'm still taking it now and I find it very reassuring that I'm still taking it now, and I've got a very sympathetic GP, who is still prescribing it for me." Interview 2

> "Another who has bald patches anyway and wears a wig full-time and she's had a mastectomy, she has persuaded her doctor that she's so worried about recurrence that she wants to remain on it the rest of her life. She's a little bit older than me but she wants to be on it." Interview 9

One participant talked about the fact that she was not told when she reached the end of the treatment and how she needed to ask about it herself, which made her feel abandoned and forgotten. Another woman shared a similar experience and decided to go with it and not stop the treatment.

> "I don't think that was handled very well because I was thinking, well if I hadn't have initiated this conversation would I have just continued to take the drug? But it was because I knew at the outset that it was for a period of time that I asked about it. Nobody brought it up with me, and I think that's a concern because you do feel forgotten about then." Interview 1

> "They didn't tell me at the time and I'm still taking it now and I find it very reassuring that I'm still taking it now, and I've got a very sympathetic GP, who is still prescribing it for me." Interview 3

Another concern some women expressed was whether their healthcare provider's suggestion for them to stop the treatment was actually in their best interest or might have been made due to financial concerns on the part of the healthcare system.

> "I suppose that was a more critical point. Whether or not it was beneficial to have continued with it or to stop it, and was I, was the decision to stop it, which was taken by the professionals because they'd obviously decided to prescribe it for this period of time, was that based on the right criteria, for the right reasons, in the patient's best interest? Or was there some financial constraints, because at the time I knew I was taking quite an expensive drug, when it first started, but I had, knew that I had access to the best choices at the time, so yeah, that was fine." Interview 1

> "I did feel a little bit well. I wonder if this is just a cost thing for the NHS. Whether it's about cost rather than it truly being only a, there's only a one percent benefit so it's negligible." Interview 11

Ultimately, reaching the end of the treatment and deciding whether to stop the medication was shown to be a dilemma in itself. Most women found the decision difficult, some deciding to continue treatment, others to discontinue it – not without fearing the possibility of recurrence.

Context: Accepting a prescription for adjuvant hormonal therapy

Women are prescribed tamoxifen or aromatase inhibitors as adjuvant therapy after surgery, radiation or chemotherapy for breast cancer. Guidelines recommend the use of tamoxifen in pre- and post-menopausal women for five years and could be extended more than that if needed. Also, the extended use of aromatase inhibitors after the initial five years after diagnosis has been encouraged in post-menopausal women.

Ability to adapt to the side-effects of the treatment

Causal conditions	Actions/interactions	Consequences
Trust and belief in the treatment and its necessity versus fear of treatment and its side-effects	Looking for appropriate support from specialists, GPs, nurses, pharmacists, support groups, family and friends	Adhering to the treatment despite being surprised by the challenges and the severity of the side-effects (i.e. finding adherence to be more difficult than originally thought)
Wanting to continue living cancer free (realizing necessity of the treatment) and fearing cancer recurrence (anticipating regret)	Looking for other sources of information	Forgetting to take the treatment as prescribed occasionally or taking a drug holiday to manage side-effects
Receiving correct information about the treatment and side-effects in advance	Trying to manage the side-effects	Committing to finishing the whole duration of the treatment
Need for knowledge vs preference for not knowing (psychological burden)	Monitoring the side-effects	Putting up with side-effects of the treatment
Severity of side-effects experienced or feared (*e.g. menopausal or psychological)*	Experimenting with alternative medicine	Suffering from the side-effects of the treatment
Ease of access and availability of professional support and perceived their trustworthiness	Discussing the possibility of changing the hormone therapy medication or changing to a different brand	Restricting social activities
Communication between different health care sectors	Asking for help and support	Side-effects of the treatment, old age and other medications get entangled
Limit of healthcare providers' knowledge	Modifying life to adapt to the treatment and its side-effects *(e.g. quitting work due to lack of energy, downsizing, changing other routines such as sport/exercise, social activities, traveling, housework and frequency of sexual intercourse, taking up healthier eating habits)*	Cancer and feeling ill linger throughout the treatment
Wanting support from family, friends, co-workers and other patients.	The use of coping mechanisms to ease the experience (e.g. active coping and self-motivation, seeking physical and emotional support, maintaining a positive attitude, meditating, acceptance, humour)	Cancer treatment taking a back seat to other priorities
Obligations to family to get well and owing it to others to live	Incorporating medication into routine and watching for changes in usual routine	Feeling lost dealing with the bureaucracy in the health care system
Ability to ask for help (fear of being a burden)	Keeping a journal to record all breast cancer related issues	Missing out on important tests or being unaware of important milestones
The perception of the treatment (positive or negative)	Asking for tests, important dates and appointments	Keeping cancer diagnosis a secret
Continue feeling as a cancer patient throughout the treatment, even though being told that they are cured, and cancer is completely gone		**Balancing priorities: adhering to the long-term treatment**
Ability to always remember to fill the prescription and take the medication as prescribed		
Changes in the patient's usual routine		
Expense of the medications (insurance issues)		
Having other priorities (e.g. work, motherhood or supporting others).		
Bureaucracy in the healthcare system		
Uncertainty about reaching the end of the treatment		
How cancer is depicted in a society (*Taboo or acceptable?)*		

Knowledge about the treatment

Support throughout the treatment

Figure 5-5: The paradigm model for the category 'Balancing priorities: adhering to the long-term treatment' (verified and corrected).

5.3.2.15 Modification to the paradigm model for the category 'Balancing priorities: adhering to the long-term treatment'

The data from the interviews matches what was identified in Chapter 3. However, some new additions to the model were recognized and described above. The additions are the following:

5.3.2.15.1 Causal conditions:

One of the causal conditions identified was the lack of communication between the various health care sectors in some cases. Participants mentioned that different healthcare providers showed no interest in interfering with someone else's prescription and tended to disregard issues related to hormone therapy, suggesting that the participant should contact her oncologist.

> "It's hard to get an appointment at the doctor's anyway, and as I say, I don't really feel as if they're that interested in this. They just say, oh yeah, well the oncology prescribe them so, no one's ever reviewed it." Interview 3

> "I tried to talk about it to my, one of the doctors at the practice, the one who takes my blood because he's the best one, but he wasn't, he just thought I should talk to the oncologist about it." Interview 9

Another causal condition is the limit of healthcare providers' knowledge. This could be due to a given healthcare provider's lack of training to deal with breast cancer-related issues, or simply to the information not being available or discovered.

> "Nowadays you get a 12-month follow-up following your treatment. So it means that the GP is the person that is dealing with the hormone treatment and unfortunately they really don't have the information that they need to deal with. So again it's about education, it's about GP education. I mean if you talk to a GP, I do go to various conferences and lectures and what have you, and if you talk to the GPs they really do feel that you're having a go at them all the time. And that's not what we're saying. We're just saying that the powers that be need to make

sure that GPs, I don't know how you do it because they do have access to the information, but they just don't do it." Interview 13

"I don't think they, I don't think it crossed their minds, I don't think they were withholding information from me, I don't think they, I don't think they knew it." Interview 14

Another causal condition is participants' ability to ask for help. This was pointed out by a participant who found it difficult to ask for assistance and feared that by doing so she might become a burden on the healthcare system, taking time from someone who might be in need of help more than them.

"Some people would find it very easy to just ring up their breast cancer nurses and say, Oh, this is happening, that's happening, what do I do, is this correct, is that correct, but there are other people, that that is extremely difficult, and one of those people is me. And then you feel like, you're taking the appointment of somebody else that may be desperately need to see the doctor whereas, I'm just asking information. I feel like I'm taking their time up when there's probably someone else that needs them more than I do." Interview 6

Having other priorities is a distraction, though one that in some cases took a toll on participants' focus on healthy non-stress living. Some priorities that were mentioned by some participants are work, motherhood and prioritizing other people's problems over your own.

- Work

"It had just taken so much of a toll in every way, physically, emotionally, psychologically, that looking back on it I think I probably should have done a phased return to work. But, of course, there were financial implications, because you can take six months on full pay, and then after that it's half pay, and I have a mortgage to pay. And that was partly why I did the flexible working, so that that could go against the sick leave period. When you have PhD students, the support you give to them, you can't measure that in hours, actually. And also we're quite

a small department and I'm in film, theatre and television, and I'm on the theatre side, which is quite small, quite a young team. So I see mentoring responsibilities as being quite important there, plus, of course, my own research. So it's very difficult for that not to take up all your time, and that's something I'm working with, is that idea of really trying to pull back." Interview 4

- Motherhood

"Yes, if I was about to have another child. But if not, then no, I don't think so. I normally comply with what they tell me to do, to be honest, because other people they have more evidence on how to treat stuff, so I say, OK fine, I'm not an expert in this area so I follow instructions." Interview 8

- Supporting others

"Yeah, and also my, I had, my daughter had a very serious problem with her eyes and I think when you've had children, you really worry about them, and when, and I had many sleepless nights pacing the floor with adrenalin with her, when I had my cancer diagnosis I didn't even lose a night's sleep with it, so I think it's having kids. Also my children would have been able to look, they were older, they weren't babies, so I think that made me, and also it's just my nature. I'm just somebody that's going to roll with it if you like, so yeah." Interview 5

The bureaucracy of the UK healthcare system and the hoops women have to go through to obtain tests, medications or to just meet a specialist, was identified as another causal condition. Some women found bureaucratic complexities − working out the steps they needed to take to get what they needed − a difficult aspect of the treatment.

"Yeah it would be something that I would really love to have when I have an issue, can I see the oncologist, obviously the NHS doesn't work like this. You have to go through several steps in order to reach the specialized doctor. In Greece as well it's like this. You go to the doctor that you want, whenever you want, whenever you feel that you want to see it rather than waiting to get an appointment whenever, yeah. OK." Interview 8

Another causal condition identified from the interviews concerns uncertainty about reaching the end of the treatment. Not everyone knew when they had reached the end of line. One participant talked about the fact that she was not told she had reached the end of the treatment and had to ask about it herself. Another participant shared a similar experience she had before deciding to continue rather than end the treatment.

> "I don't think that was handled very well because I was thinking, well if I hadn't have initiated this conversation would I have just continued to take the drug? But it was because I knew at the outset that it was for a period of time that I asked about it. Nobody brought it up with me, and I think that's a concern because you do feel forgotten about then." Interview 1

> "They didn't tell me at the time and I'm still taking it now and I find it very reassuring that I'm still taking it now, and I've got a very sympathetic GP, who is still prescribing it for me." Interview 2

Another causal condition is how cancer is depicted in a society and whether discussing a cancer diagnosis is taboo or acceptable. Some participants spoke about their preference for keeping their cancer diagnosis a secret, others about how cancer is still a taboo topic, so that talking about it with strangers can still be difficult for some survivors.

> "The only thing I was, the only time is, you're having it, that's fine, you're getting on with it, then you lose your hair and then you know that everyone knows you've got it, and that's, I'd rather people didn't know. Not because I'm embarrassed but just because I didn't need them to know. Do you know what I'm saying?" Interview 5

> "And some people still fear cancer. The taboo's being broken down but there is still, I don't know if there is in your country, but here there still is a taboo about, a bit of a taboo about cancer, not as much as it used to be." Interview 14

5.3.2.15.2 Actions/interactions:

One of the actions identified from the interview was the monitoring of side-effects. One of the side-effects mentioned by women was osteoporosis; participants talked about the advantages of having regular bone density scans to monitor bone health.

> "My consultant wrote a letter and then I had a letter from the GP, saying yes they'd arrange for me to have a bone density scan, and then I found that I'd osteopenia and so they prescribed alendronic acid for that, so I was taking that at the same time as taking the Arimidex, yeah." Interview 1

> "I should also say, because this is part of the whole pharmaceutical package that I'm on, I also have osteoporosis. So that is a side-effect of Anastrozole, which I'm on. So I also have to take alendronic acid, which is an awful nuisance. But I can see that, I've had a couple of bone scans since then, and the bone density is increasing." Interview 4

Another action identified from the interviews was women asking to change the brand of the treatment to reduce their side-effects. As shown above, the reported experiences show a clear difference in some cases where participants reported having a better experience with one brand of the treatment than with another.

> "Although I don't know if the other, anybody else has said this, there are different types, there are different manufacturers of these tablets and with one manufacturer it, I had very, I had really stiff muscles, bones, my ankles were really sore and I've found that if I stick to certain manufacturers of letrozole I am much better. So if I, I now put on my prescription, I do not want this brand of letrozole and I don't know. Yeah I have told somebody else this as well, her elderly mother took some and she asked for a different type as well and since the side-effects seem less. So I don't, it's just one of these things, it might just be, I don't know, no but it definitely, yeah." Interview 12

> "I do obviously know but there are different generic, there are different manufacturers and they're not necessarily exactly the same and so my suggestion

> if they're having problems would generally be if you feel that you want to give up, first of all I would reassure them that it's not normal whatever it is they're doing, that they're getting if it is, and then I would suggest that if they suggest they don't want to come off it, they want to come off it I will obviously tell them about the benefits of it. But also I will say to them to go back to their GP or their consultant depending on which stage they're at to actually suggest that they perhaps take a different type because I've had quite a few people that have gone from one to another and found that one suits them so much better. So that's not something, again that's not something that's usually mentioned during a consultation. So it's quite important really." Interview 13

Another action identified from the interviews was women asking for help and support during the treatment. Not everyone has the capability to ask for help, and some women find it difficult as shown in the previous part of the results, but generally speaking women tried to find someone able to provide them with the help and support they needed to navigate their experience.

> "Yeah, I think so, even if it's just a nurse. It doesn't have to be the doctor, it's just someone to say, 'How are you getting on? What are your side-effects like?'." Interview 3

> "I don't think it's anybody's fault, the doctors and the oncologists, they have to see so many people that there probably isn't the time, and, I guess, maybe my case wasn't as severe as many others, so, though other people needed their time more than I did, but, mentally, I think I needed the time. Maybe not physically, but mentally." Interview 6

> "So, well, the support I needed was something to take the edge off the worst symptoms, to make them manageable and that really is from people like yourself and medicine and specialist nurses I think, really." Interview 14

Keeping a journal to record all breast cancer-related issues was another action taken by some women. Writing everything down helped them remember their experiences and was

shown to be helpful when they discussed progress with their healthcare providers during their follow-up visits.

> "Because this is my little book you see, so all the way right from the beginning I wrote everything down, because I thought I can't, you can't remember." Interview 10

> "Yeah and I think that's what I would say to people as well, is to write everything down, how you're feeling, keep a diary so that when the doctor says to you, 'And how are you?', you don't say I'm fine, you can say 'actually I'm OK now but two weeks ago I was feeling really sick'." Interview 12

Women also mentioned sometimes having to ask for tests, important dates and appointments themselves.

> "The other thing I looked into, which wasn't picked up in the hospital, was the danger of raised cholesterol and hypertension. My family has quite a history of cardiovascular disease and both my parents died of heart attacks. So I went to the GP and asked to be tested, and lo and behold my cholesterol was up and my blood pressure was all over the place." Interview 14

5.3.2.15.3 Consequences:

One of the consequences identified from the interviews is that in some cases cancer treatment can take a back seat to other priorities such as motherhood, work or supporting others in need.

> "Yeah, and also my, I had, my daughter had a very serious problem with her eyes and I think when you've had children, you really worry about them, and when, and I had many sleepless nights pacing the floor with adrenalin with her, when I had my cancer diagnosis I didn't even lose a night's sleep with it, so I think it's having kids. Also my children would have been able to look, they were older, they weren't babies, so I think that made me, and also it's just my nature. I'm just somebody that's going to roll with it if you like, so yeah." Interview 5

A consequence of bureaucratic complexity is that sometimes breast cancer survivors might feel lost within the healthcare system.

> "I spoke to my GP about it and having a bone density scan, and they told me that I wasn't entitled to have one. I was concerned for two reasons. One that, well I'd had a few joint pains and aches and pains but then I thought that was, that could have been anything at my age whatever, but also because I'd had radiotherapy and I knew it was, well the risk factors with taking the treatment and it wasn't, so I, she went through various criteria, told me I wasn't entitled, and I went back and spoke to them in the hospital. My consultant wrote a letter and then I had a letter from the GP saying yes they'd arrange for me to have a bone density scan, and then I found that I'd osteopenia and so they prescribed alendronic acid for that." Interview 1

> "Yeah it would be something that I would really love to have when I have an issue, can I see the oncologist, obviously the NHS doesn't work like this. You have to go through several steps in order to reach the specialized doctor. In Greece as well it's like this. You go to the doctor that you want, whenever you want, whenever you feel that you want to see it rather than waiting to get an appointment whenever, yeah. OK." Interview 8

Another consequence identified in the interviews was women missing out on important tests or being unaware of important milestones.

> "I don't think that was handled very well because I was thinking, well if I hadn't have initiated this conversation would I have just continued to take the drug? But it was because I knew at the outset that it was for a period of time that I asked about it. Nobody brought it up with me, and I think that's a concern because you do feel forgotten about then." Interview 1

Due to the taboo nature of cancer and how the society depicts it, some women might decide to keep their cancer diagnosis a secret.

> "And some people still fear cancer. The taboo's being broken down but there is still, I don't know if there is in your country, but here there still is a taboo about, a bit of a taboo about cancer, not as much as it used to be." Interview 14

5.3.3 Taking a chance: stopping the treatment early

Some women take the decision to stop the treatment early, as shown in Chapter 3. In my interviews one participant talked about how the treatment affected her life negatively, making her feel tired and in constant pain, until she felt she was hardly living at all. She felt she was taking the treatment to merely "exist", not to "live".

> "And I think that's an important thing, you're, for me it was an existence, it was not living at all." Interview 14

Despite her dedication and commitment to taking the treatment for the original five years, when recommended to continue on it further she refused.

> "Oh, once I got to the end, my last, yes, because then there was new research out and what they wanted me to do was take it for another two years and I just said 'no'." Interview 14

The treatment was crippling, and it was not just her quality of life that was affected. She felt the treatment impacted every aspect of her life. The treatment and its side-effects became her sole focus and by the end consumed her entirely.

> "It's joining up the dots, when it's crippling, when it's crippling and it's for a number of years − we're not talking about a few months here − out of your life, you give up your life when you're having something like this, to a certain extent, well to a big extent for me, actually." Interview 14

She felt that had the side-effects not been so bad, she might have continued on the treatment longer. But by the end, the cumulative effects of breast cancer, hormone therapy and the continuous infections made her decide to stop. The treatment interfered

with her life so much that she reached her breaking point, making her feel she had no option but to stop.

> "Well when it came, had the experience of taking it not been so bad, I probably would have gone on for the next few years. Having discussed that with the people in the osteoporosis clinic as well, can I go on having the intravenous zoledronate and things like that, I probably would have thought OK, if it wasn't interfering with my life, but the effect on my life, the cumulative effect of everything, I was so weak when I started the cancer treatment and I just, I, you could have knocked me down with a feather, it was hell, it was hell and I just thought, 'no'." Interview 14

When asked about her reasoning, she replied, "What's the point?". She felt that had she been younger, she might have persisted with the treatment longer, but took the decision to stop as she had reached the stage of valuing quality of life over longevity. This reasoning is quite similar to that of another interviewee, who thought that had she been older she might have decided against taking the treatment.

> "What's the point? This was, the chemo was hell, and then another five years of hell, am I going to have another two years of hell, that's over seven years. What's the point of this treatment, why was I treated for breast cancer in the first place? To have a life. Maybe if I was a lot younger, I would have thought maybe, maybe that'll increase my chances. I was 61 when I was diagnosed. I'm not going to live forever, I would like to have some quality of life. So, I just thought, 'no'." Interview 14

> "I do agree with that. I think if I was older I definitely wouldn't take it, definitely no." Interview 3

Stopping the treatment and regaining a sense of normalcy in her life made the participant feel "psychologically brilliant". Although stopping the treatment did not have a sudden physical effect, the participant nevertheless reported feeling much better. Physically, it took the participant four years after stopping the treatment to 'feel her old self'.

> "Psychologically brilliant; physically there was no sudden change." Interview 14

> "Yes, after the, so October 2015 I stopped the letrozole and where are we now? October 2019. It was only earlier this year that I really felt it had finally, because even a slight thing would trigger a headache and my viral infection, everything." Interview 14

One more reason mentioned in the interviews for stopping the treatment was being given the choice to stop by the healthcare provider, which matches the findings from Chapter 3.

> "I have another friend, an older colleague who works at the library and she stopped taking it because she was advised to." Interview 9

Another participant was similarly given the choice by her healthcare provider to either continue on the treatment or stop it after the initial five years. Her healthcare provider felt that despite the benefits of continuing on the treatment, they were outweighed by the side-effects.

> "When it came to my five years, end of my five years, they had got the benefit of that study and when I spoke to my consultant about, I understand that if you take it for ten years then you're, there is a benefit to that, he told me that the benefit was only about one percent, so it wasn't worth the, it wasn't worth taking it for ten years for a one percent benefit of not getting breast cancer, balanced with bones crumbling." Interview 11

She also talked about a family friend who decided not to undergo the treatment and instead to take her chances with cancer.

> "Like my mum's friend that had breast cancer and decided that she didn't want any treatment, she didn't, she just, so I do actually, through my own experiences, know that this happens." Interview 11

One participant who survived breast cancer and was now involved in supporting others, talked about how some women might have issues with prescribed medicines in general. These women might decide to stop their treatment due to a lack of trust in it and/or in the medical system itself, or simply be due to their fear of the potential side-effects.

> "You do get the odd ones who don't actually want to take them at all because, and they usually have some sort of problem with prescribed medicines overall. But I've come across that as well, where people don't want to take tablets." Interview 13

> "Yeah, I think it's just if someone has got a real block about taking prescribed medicines, putting stuff − as they see it, poison − into their bodies, they really don't want to do that. And other people, the reason they don't want to take it is because they're getting bad side-effects." Interview 13

The same participant also mentioned those people who start the treatment for a while, suffer from the side-effects, then decide to stop.

> "Yeah, some people, yeah, some people will take it for a while and hope that they might, it might go away and then when it doesn't they then say, no, do you know what, I'm not going to take it anymore. I think that it's, I think it's, that again is a matter of choice." Interview 13

When asked whether participants might decide themselves to stop the treatment, without discussing their decision with anyone, her answer was consistent with the findings from Chapter 3:

> "Yeah, sometimes they do it on their own. They don't take, talk to anybody else." Interview 13

Another reason for ceasing treatment was participants' changing priorities while taking the medication. When asked whether she might consider stopping the treatment prematurely, one woman talked about the possibility of doing so if, down the line, she

decided to have another child. To her, having another child would in that eventuality have taken priority over continuing her treatment.

> "Yes, if I was about to have another child. But if not, then no, I don't think so. I normally comply with what they tell me to do, to be honest, because other people they have more evidence on how to treat stuff, so I say, OK fine, I'm not an expert in this area so I follow instructions." Interview 8

<table>
<tr><td colspan="5">Context: Adhering to the medication and experiencing the side-effects
After starting the treatment and committing to adhere, women start to experience the medication side-effects, which is unexpected or more severe than they had imagined or expected</td></tr>
<tr><td rowspan="2">Quality of life taking precedence over longevity of life</td><td>Causal conditions</td><td>Actions/interactions</td><td>Consequences</td><td rowspan="2">Continuous search for normalcy</td></tr>
<tr><td>Severity of the treatment severe side-effects
Poor quality of life
No trust in the treatment (i.e. negative perceptions of the treatment)
Fear of the possible side-effects
Being given the choice to stop the treatment by the healthcare provider
Faith and religion
A sense that existing adherence has already conferred therapeutic benefit
Lack of support during the treatment
Lack of trust in the healthcare providers and the medical system
Having a different priority</td><td>Communication with healthcare providers and deciding to stop the treatment
Stopping the treatment without communicating with anyone</td><td>Stopping the treatment early
Accepting that death is not the worst option
Better quality of life
Regaining control
Having a sense of normalcy
Taking a chance: stopping the treatment early</td></tr>
<tr><td colspan="4">Beliefs about the treatment’s necessity</td></tr>
</table>

Figure 5-6: The paradigm model for the category ‘Taking a chance: stopping the treatment early’ (verified and corrected).

5.3.3.1 Modifications to the paradigm model for the category 'Taking a chance: stopping the treatment early'

This model was found to be all-inclusive. The only addition to it is the causal condition of having a different priority over the treatment. The data from the interview suggest that a woman might start to prioritize something that could not be achieved while on the treatment, such as having another child. Opting to pursue such a priority could be a reason for some women deciding to stop the treatment.

> "Yes, if I was about to have another child. But if not, then no, I don't think so. I normally comply with what they tell me to do, to be honest, because other people they have more evidence on how to treat stuff, so I say, OK fine, I'm not an expert in this area so I follow instructions." Interview 8

5.3.4 Core category

The core category identified in Chapter 3 is "Hobson's choice or a horned dilemma?". The findings in this study match those identified earlier. Some participants did not think they had a choice in the matter of their treatment, the decision to take it feeling like Hobson's choice. Below, we see multiple quotes in which participants report their lack of choice in the matter, given that the alternative to taking the treatment was "dying early".

> "Just that, that was the only choice I had, It is a strange feeling that, you feel like you just have to do what you're told. But I don't feel there was a choice for me." Interview 6

> "Yeah, you have to take it because otherwise, it's the otherwise, what would happen if you don't take it. So you have no other choice to be honest, yeah that's true." Interview 8

> "Yeah, it is Hobsons's choice really, I haven't thought of not taking it. So yeah." Interview 10

> "As far as I was concerned, if it kept me, if it meant that I wasn't going to die quite so young, then I was quite happy to do so. You kind of don't feel you have a, well you do have a choice, you can turn around and say, no I'm not doing that, I'll let the cancer run its course and potentially die early. Or you go, no I'm not, I'm not, I'm not doing that, it's not, I'm, I'm not ready to, to leave this planet, so I'm going to do whatever I have to do to keep my life going for as long as I can." Interview 11

On the other hand there is the horned dilemma with the treatment, where participants struggle on a daily basis with the decision of whether to continue or stop on the treatment − as demonstrated by the first quotation below. Another participant talked about the attitudes of different survivors and how some might take the decision to stop the treatment while others never would.

> "When you get out of bed in the morning and then you have trouble even starting to walk and it can take a couple of hours to get your joints going again, or it's like, when I'm sitting in the office sometimes, and I absolutely feel like I'm going to combust because I'm so hot. And any minute now you think your whole body's going to blow apart, but the thing is, is, you could stop the drugs and die. It's weighing it up, isn't it? And, I guess each one is different in what our priorities are." Interview 6

> "Yeah, yeah. So I can see that that does encapsulate both, both, all different characters or both sides. There are some people that go, I'm going to fight it regardless, and there are others that go, you know what, I don't care, I'm going to give up, like my partner did. Yeah, that's very good. And I can see this in respect of some of the ladies within the breast cancer group where some of them have gone, you know what, I don't care anymore." Interview 11

Lastly, there are two quotes from one participant who took the decision to stop treatment after taking it for five years. This quote shows that the participant's perception of the treatment changed from that of it being a Hobson's choice in the first quote (relate to the start of the treatment), to a horned dilemma in the second quote (relate to the five years down the line). The change of perception was caused by the participant's bad experience.

"Yeah, it is Hobsons's choice really, I haven't thought of not taking it. So yeah." Interview 14

"Oh, once I got to the end, my last, yes, because then there was new research out and what they wanted me to do was take it for another two years and I just said 'no'. "What's the point? This was, the chemo was hell, and then another five years of hell, am I going to have another two years of hell, that's over seven years. What's the point of this treatment, why was I treated for breast cancer in the first place? To have a life. Maybe if I was a lot younger, I would have thought maybe, maybe that'll increase my chances. I was 61 when I was diagnosed. I'm not going to live forever, I would like to have some quality of life. So, I just thought, 'no'." Interview 14

5.4 Discussion

The findings of this study support what I identified in Chapter 3. Women on hormonal treatment for the management of breast cancer fall broadly into three groups. The first involves thinking of the treatment as a Hobson's choice. Here, women are more likely to adhere to the treatment, due to their belief in its necessity, which has the effect of making them more tolerant of the treatment's side-effects. The second involves thinking of the decision to continue with medication as a horned dilemma. On encountering difficulty during adjuvant endocrine therapy some women are more inclined to give up the treatment; they are less tolerant of its side-effects and their belief in its necessity is not as strong as that found in the first group. The third involves beginning the treatment while thinking of it as a Hobson's choice, but views starting to change when adherence becomes difficult, at which point the decision about whether or not to persist with the treatment becomes a horned dilemma.

The change in perceptions does not happen overnight. It is an active process, unfolding as the participant passes through multiple experiences (either positive or negative) over the period of the treatment. These negatives occupy an area in which healthcare providers need to intervene, for if these experiences are not somehow improved they have the

capacity to strongly influence the perception of survivors of breast cancer, turning what was once a Hobson's Choice into a horned dilemma. It is then that survivors struggle with the difficult decision of whether to continue the treatment or cease it, weighing the positives and negatives continuously until they perhaps reach breaking point and decide to discontinue the treatment. This additional insight was gained through face-to-face interviews. Conducting a meta-synthesis and dealing with only quotations was not the same as completing a full interview study and analysing a full dataset of interviews. The meta-synthesis study's quotations failed in capturing the dynamic sense of the participants' experience. This was much more obvious in the interview study as I was speaking to women and later dealing with full interviews where capturing the dynamic progressive nature of the treatment and the participant experience was considerably easier.

I conducted 14 interviews for my study, of which 11 were completed face-to-face and the remaining three via telephone. Despite the interviews being conducted in these two different settings, they were all quite similar. However, there are some differences between the two approaches that are worth exploring. Requests for clarification and interviewees checking the adequacy of their responses were more common in the telephone interviews. This is in line with the findings of Irvine et al. (2013). The length of the two types of interview was different as well. All three interviews conducted by telephone were above an hour in length, while only two of the 11 face-to-face ones exceeded the hour mark. Interviews carried out by telephone were longer than those completed face-to-face. This contradicts the findings of Irvine et al. (2013) and Novick (2008), who state that interviews conducted by telephone are usually shorter. The reasons they provided is that telephone interviews are strenuous and require more concentration from both interviewer and interviewee. My findings suggest differently. Despite requiring more concentration, all three telephone interviews took place while both interviewer and interviewee were at home. This made the interviews flow in a friendlier manner and establishing rapport was simpler. Also, participants were noticeably more open about sensitive topics and happier to speak about awkward issues during telephone interviews. The lack of travel time was another positive for both interviewer and interviewee, making the process simpler on both sides. The only negative I found in the telephone interviews was the absence of visual cues, namely body language and especially facial expressions. However, due to the particular nature of these interviews,

physical cues were not of significant importance to me and my research. Conclusively, I found both types of interview to result in a similar amount of data and the differences between the two settings to be negligible.

The importance of knowledge is very evident at the different stages of the treatment. It does not just facilitate the whole process; it also contributes greatly to participants' decision-making process. The influence of knowledge on adherence is consistent with the findings of Bourmaud et al. (2016), Wouters et al. (2013) and Cahir et al. (2015). In some cases, even if participants lack the knowledge themselves, having a friend or a family member who is knowledgeable is quite helpful. The findings of the study suggest that participants who are knowledgeable about the treatment or have someone close who is well-informed, have reported a better overall experience. Knowledge also plays an important role in participants' monitoring of their side-effects. Not all participants go through similar paths and everyone reported a different overall experience; for instance, while some participants reported their GP offering them follow-up tests and lab work, others did not. Some of those who are knowledgeable about the treatment and their side-effects reported having to request tests such as bone density scans themselves. Those participants felt that had they not ask for these tests themselves, they would not have been offered them by their GP. Another part of the process where knowledge is important is reaching the end of the treatment. Some participants were not told about reaching the end by their healthcare provider and had to enquire about it themselves. This was not a positive experience for them, as they felt that if they had not enquired about it themselves, no one would have told them about it.

The severity of side-effects and women's ability to tolerate and manage them is one of the most important factors identified in my study. Specialist healthcare providers' inability to explain some of the side-effects of hormone therapy question the limit of their knowledge and highlight the need for further research into this phenomenon. The importance of managing the side-effects of the treatment has been mentioned in multiple previous studies (Wells et al., 2016; Rust and Davis, 2011; Farias et al., 2017). However, not all side-effects are manageable. Some are very severe, to the extent that stopping the treatment can seem a woman's only option. Further research into the reasons behind some of the reported side-effects, with a view to developing new ways to cope with them, is

necessary. Hormone therapy is a long-term treatment; expecting survivors to cope with debilitating side-effects is unrealistic and in need of reconsideration.

Support is another important factor that continually appeared in the data. The support of friends and family members during the initial stage of hormone therapy is a factor that plays an important role in participants accepting the hormone therapy prescription. Other forms of support include support groups, support from healthcare providers and support from employers and co-workers, not just at the beginning but throughout the treatment. Participants' stance about support groups varied, some find them helpful, others prefer not being involved in any. This is consistent with the findings of Helgeson et al. (2000). The findings from my study suggest that women have different needs, those who could call on good emotional support at home and from friends expressed no desire to be involved in external support groups. My findings also showed that women experiencing difficulties with side-effects-related issues did not feel that support groups could provide them with the help they needed. Job security was also mentioned by some participants; having support and consideration from your employer, and not fearing the loss of your job due to being diagnosed with cancer, is vital for a stress-free work life-balance and influenced participants positively. The importance of support in cancer care is reported in multiple studies (Harrow et al., 2014; Iacorossi et al., 2016; Brett et al. 2018; Humphries et al. 2018; Xu and Wang, 2019). Having support at home, hospital and the workplace throughout the duration of the treatment has the potential to improve women's overall experience greatly.

Breast cancer survivors meet with their cancer specialist once a year. In between these visits, GPs are the health professionals responsible for providing women with care. The data from this study show a lack of trust and belief in GPs' knowledge and their ability to provide the necessary help and support. This is in line with the findings of Rose et al. (2001) and Potosky et al. (2011). However, the issue of primary care is not only survivor-related. The literature shows confusion on the part of GPs themselves on what type of post-cancer care they should provide (Meiklejohn et al., 2016). This could be due to the fact that GPs are already overloaded with other duties and responsibilities (Johansen et al., 2010; Meiklejohn et al., 2016), or simply to the lack of communication between them and prescribing specialists (Munday et al., 2002; Meiklejohn et al., 2016). The findings in this study show unmistakably the lack of communication that exists between the

various health sectors as perceived by women cancer survivors. The findings also highlight how reluctant GPs can be to interfere in someone else's prescription and the fact that they tend only to be involved in side-effects management. Sometimes the problem relates to the overall health system. The bureaucracy and complexity of the UK healthcare system emerge from this study's findings as a vital influence on participants' experiences. Some participants showed delight and pride in their ability to work around the bureaucratic complications, specifically when it came to requesting tests and new prescriptions and inquiring about important milestones. Others were less happy, feeling that the complications hindered their experience and influenced their treatment plane negatively. The models created in this research highlight the need for a simplified system of communication and cooperation between healthcare providers and breast cancer survivors. A better model would look to reduce complications and misunderstandings in the health care setting.

Many women have difficulties speaking about cancer. The topic is still considered taboo by many. Some of the women in this study shared how difficult speaking about cancer felt to them. Some preferred to keep their cancer diagnosis a secret. This finding in my study matched those of Lally et al. (2013) and Trusson and Pilnick (2017). It is not just the stigma of cancer that prevents women from sharing their condition; some might fear the strength of other people's reactions to their news. They fear becoming a burden on their loved ones and that others might show an intense reaction, to the extent that their reactions might feel overwhelming to them rather than supportive.

By conducting the meta-synthesis beforehand, I was able to identify women's experience on hormonal treatment on a larger scale than otherwise. After all, the meta-synthesis included the views of 558 women and 24 researchers. The theory developed in Chapter 3 was comprehensive and provided good grounds for conducting the interviews. The findings in Chapter 3 were also shown to match the findings of this interview study. Completing the 14 interviews allowed me to take my initial results further and develop the models beyond what has been identified through the literature. It also allowed me to obtain some feedback from participants on the pictograms I developed as shown in Chapter 4. The feedback proved encouraging, with all 14 women identifying with the pictograms and finding their own stories in them. The improved models are the basis for developing an educational tool discussed earlier, to help survivors and non-specialist

healthcare providers better understand women's experience of the treatment. Such a tool could help breast cancer survivors communicate their experiences and worries to their healthcare providers during their consultations in a clear and simple manner. In the next chapter, I detail how I added the newly identified categories to my existing pictogram models.

Chapter 6: Pictogram updating

The previous chapter (Chapter 5) illustrated the multiple new categories identified and added to the grounded theory models first shown in Chapter 3. This meant that I now needed to revise my pictograms (detailed in Chapter 4), by updating them with the additional information which I detailed in Chapter 5 (see Figure 6-1). With the participation of the 10 panel members who helped in the validation and design of the original pictograms, I organized a focus group discussion to receive further input on the best presentation of the new categories and how to draw them. The group helped me reach a decision to draw the pictograms as seen in Table 6-1 below.

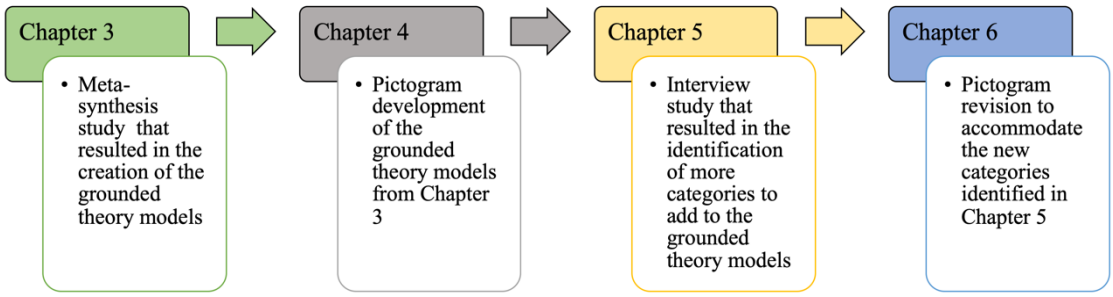


Figure 6-1: Pictogram development progress across the different chapters of this thesis.

With the help of the external designer who designed the original pictograms, the new categories were drawn and added to the models, producing the final set of models. The panel was then shown the new pictograms, which they approved. The final set of models, as agreed on by myself and my primary supervisor and my panel, is shown below Figure 6-2 for the first model, Figure 6-3 for the second and Figure 6-4 for the third and final model.

I later held a discussion with my supervisor to decide on the possible designs for illustrating the core category. The bases of the first design were sent to the external designer for him to prepare the primary sketch. After receiving the first design, we held another meeting to discuss this and decided to reject it on the bases of it not capturing the dimensions of the core category clearly and could be misunderstood. A new design idea was then arrived at and passed on to the external designer. This second design appeared to capture the core category "Hobson's choice or a horned dilemma" fittingly – this was

a decision that myself and my supervisor came to jointly, but which I again tested with my panel. The final design is presented in Figure 6-5 below.

The drawing of the core category shows the three groups of experiences for women on hormonal treatment. The first group, depicted on the left of the drawing, depicts those who think of the treatment as a Hobson's choice; here, women are more likely to adhere to the treatment due to their beliefs about its necessity and are more tolerant to the side-effects of the treatment. The second group, represented in the middle drawing, shows those who regard hormonal treatment as a horned dilemma; here, if faced with a difficulty, women are more inclined to stop the treatment, be less tolerant to the side-effects and have weaker beliefs about the treatment's necessity than the first group. The third, seen on the right of the drawing, shows those who start the treatment thinking of it as a Hobson's choice but who, when adherence becomes difficult, start to change their view, the decision of whether or not to continue on the treatment then becoming for them a horned dilemma. Underneath each figure are some of the experiences, actions and consequences which women go through during the treatment and which, as explained in the previous chapters, play a role in their decision-making.

Table 6-1: The agreed-on development of drawings by the panel members to represent the new established categories

The paradigm model for the category "Guided by the doctors: accepting the long-term prescription"	
Experiences	**Agreed-on drawings**
Lack of information/understanding	Change the text in the pictogram
Uncertainty about the medication (add pictogram)	A confused face looking at medication pills
Background differences	**Agreed-on drawing**
Support from family and friends	A happy face surrounded by family members and friends
The paradigm model for the category "Balancing priorities: adhering to the long-term treatment"	
Experiences	**Agreed-on drawings**
Communication between different health care sectors	Nurse > Doctor > surgeon > GPs
Limit of health providers' knowledge	Someone in a white coat thinking and confused
Ability to ask for help	Someone saying "help"
Having other priorities	Someone juggling family/work/medication
Working out the bureaucracy in the healthcare system	Someone looking at a maze
Uncertainty about reaching the end of the treatment	Someone reaching the finishing line in a race and looking confused
How cancer is depicted in a society. Discussing a cancer diagnosis: taboo or acceptable?	Someone talking | someone covering their mouth
Actions	**Agreed-on drawings**
Monitoring the side-effects of the treatment	A monitor with heart rate
Asking for help and support	Someone feeling lonely while surrounded by family friends
Keeping a journal to record all breast cancer-related issues	A journal

Asking for tests, important dates and appointments	A calendar with a date circled
Consequences	**Agreed-on drawings**
Cancer treatment taking a back seat to other priorities	Medication box sitting in the back seat of a car
Feeling lost dealing with the bureaucracy in the healthcare system	Someone lost in a maze
Missing out on important tests or being unaware of important milestones	Someone looking confused at a calendar
Keeping cancer diagnosis a secret	Someone covering their mouth
The paradigm model for the category "Taking a chance: stopping the treatment early"	
Experiences	**Agreed-on drawing**
Having a different priority over the treatment	Someone with a list of priorities over their head and choosing "Priority 1"

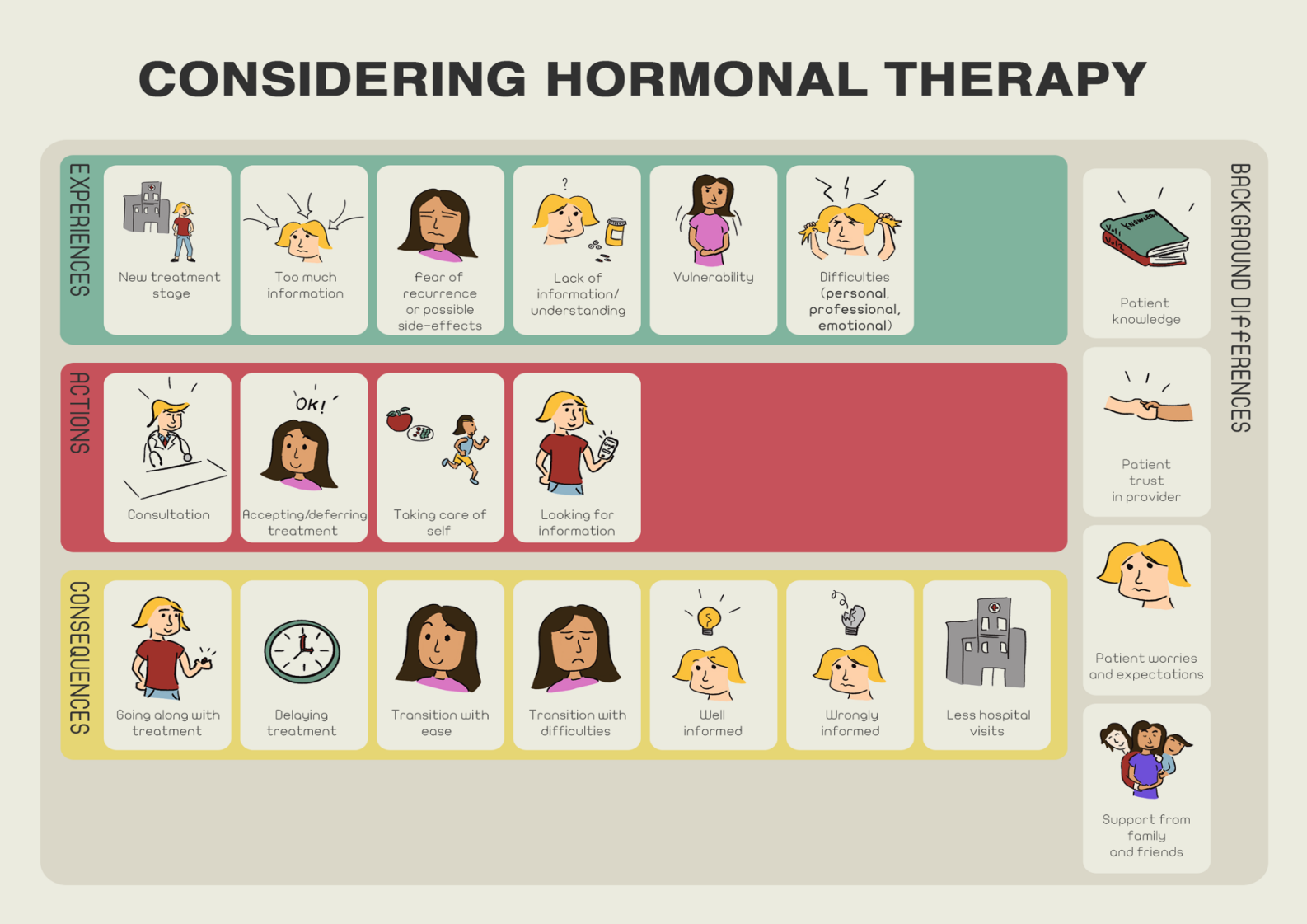


Figure 6-2: The paradigm model for the category "Guided by the doctors: accepting the long-term prescription" (verified and corrected).

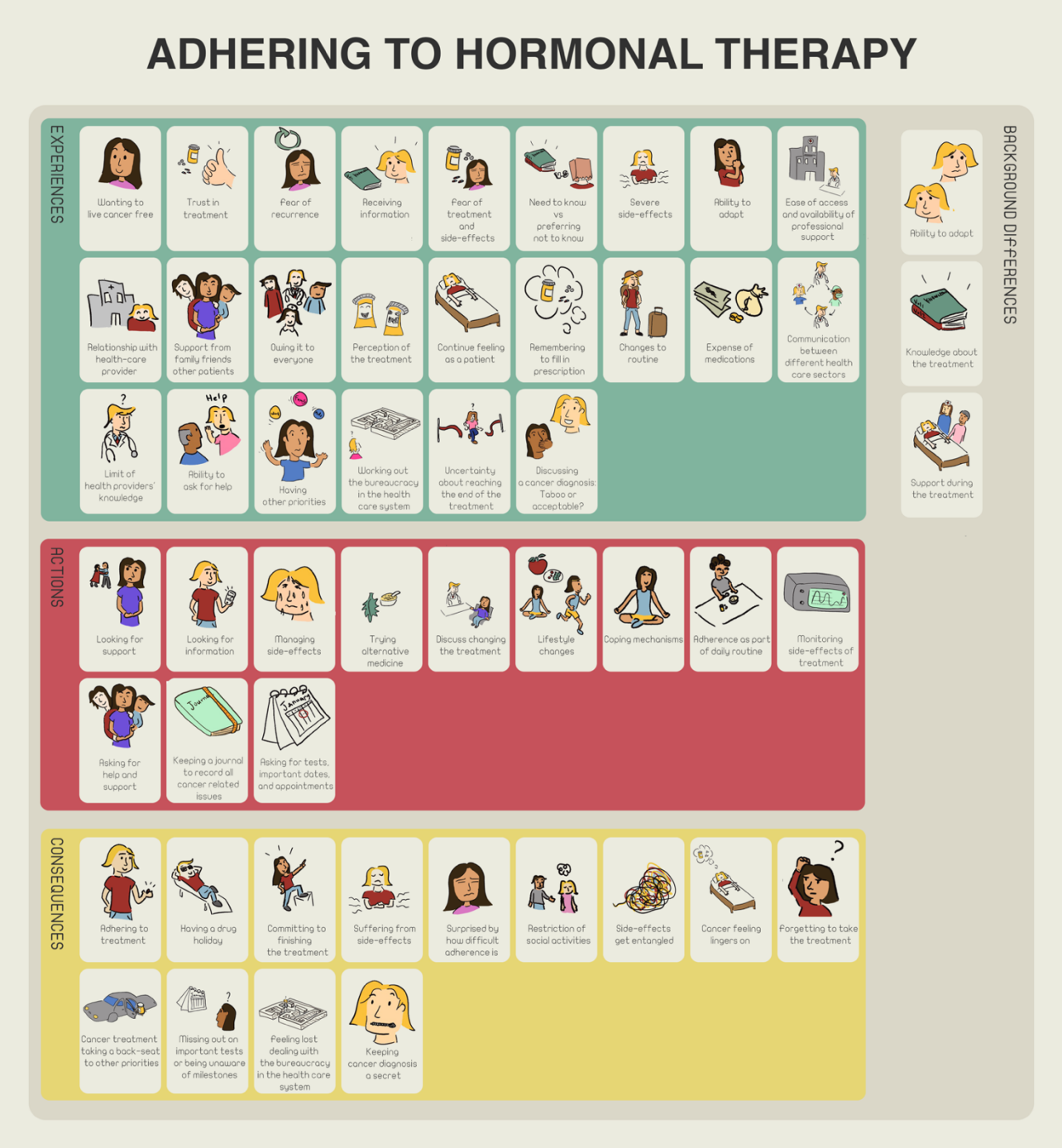


Figure 6-3: The paradigm model for the category "Balancing priorities: adhering to the long-term treatment" (verified and corrected)

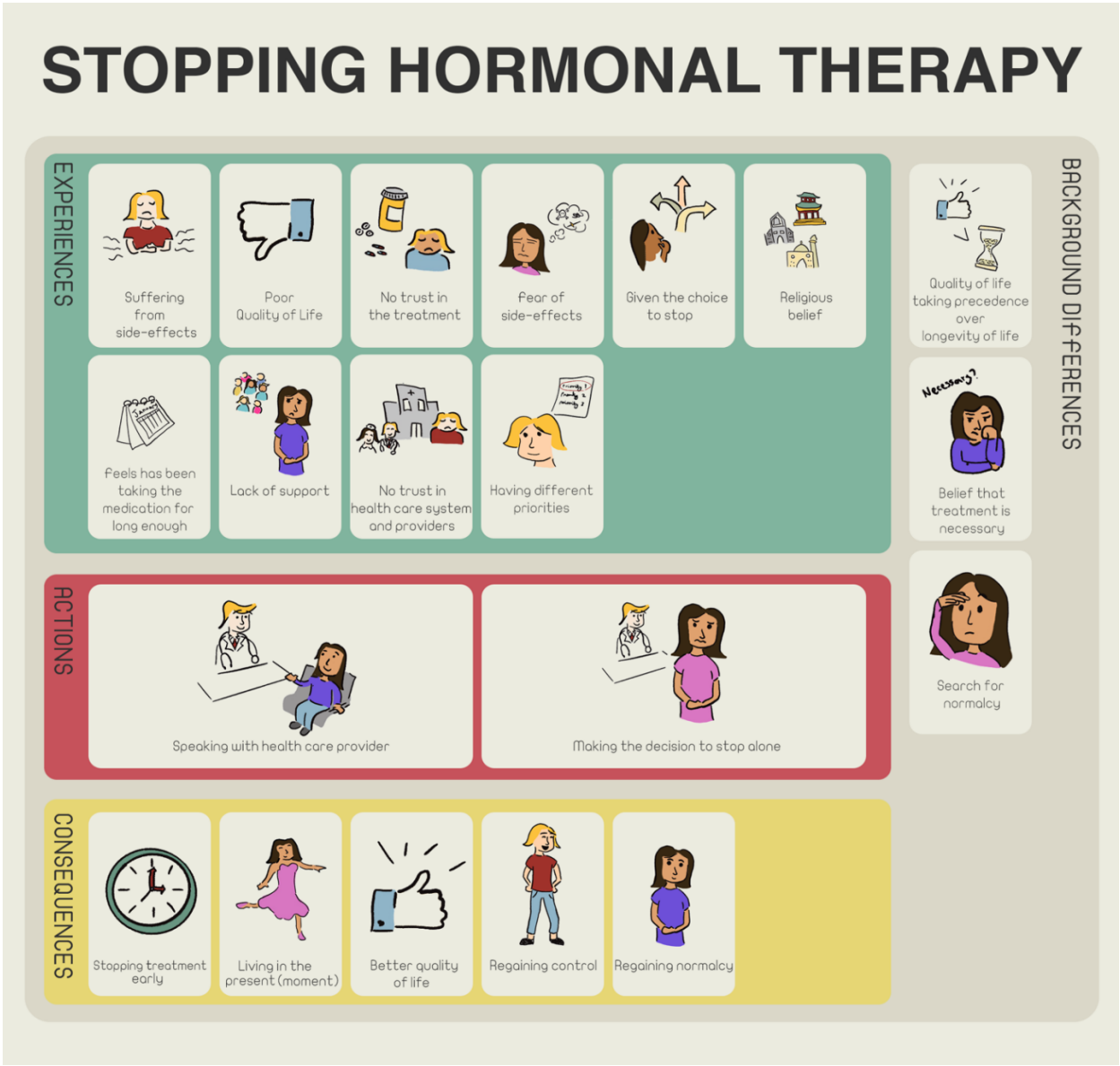


Figure 6-4: The paradigm model for the category "Taking a chance: stopping the treatment early" (verified and corrected)

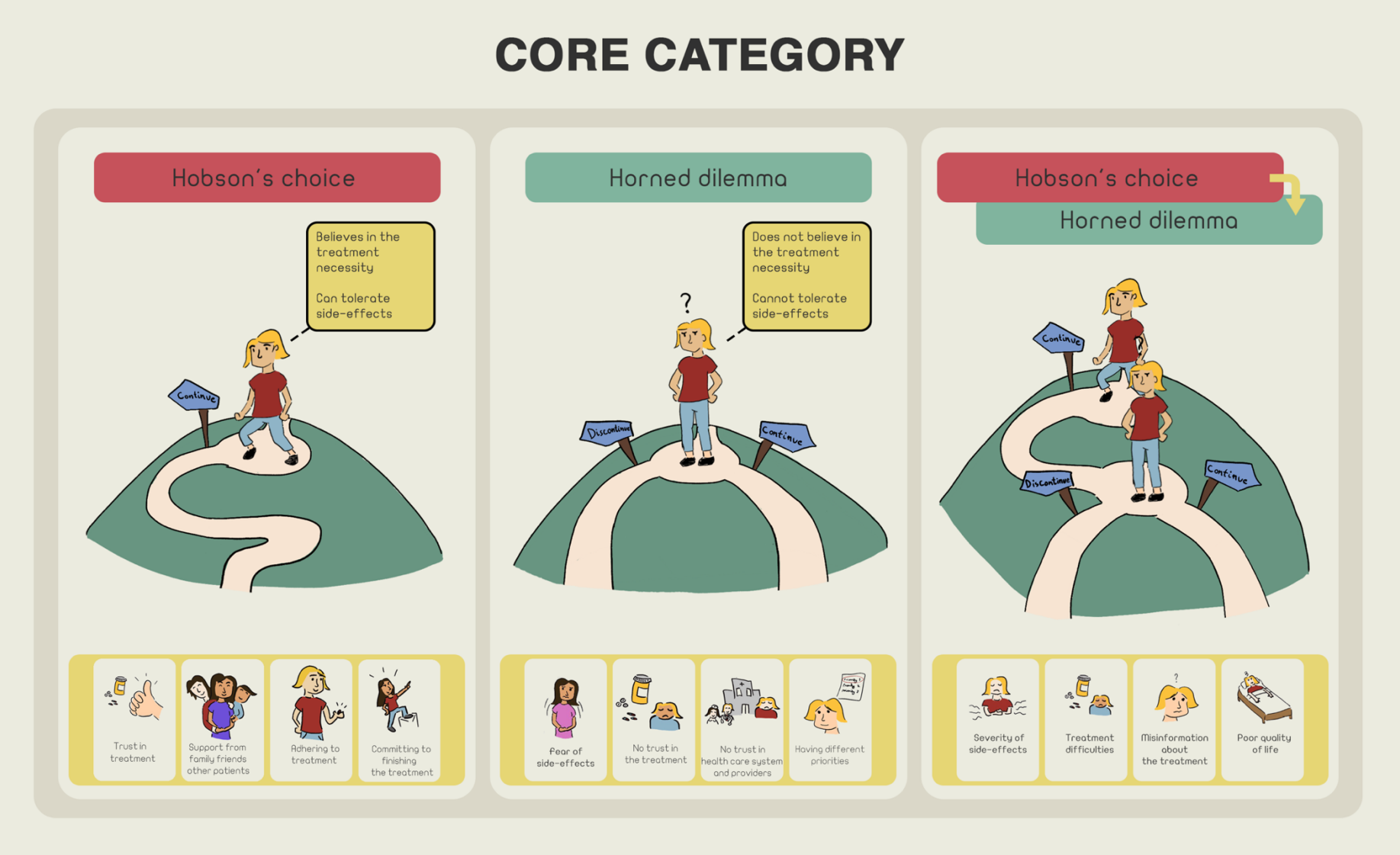


Figure 6-5: Core category "Hobson's choice or a horned dilemma?" (verified)

Chapter 7: COM-B Model and possible interventions

7.1 Introduction

Human behaviour has been defined as "the product of individual or collective human actions, seen within and influenced by their structural, social and economic context" (NICE, 2007). In this thesis I have looked in detail at women's non-adherence to oral hormonal medications in the management of breast cancer. As described earlier, the literature shows variation in adherence to oral anticancer medication in patients diagnosed with breast cancer. Medication non-adherence in this patient group has thus been shown to be an issue worth investigating. In the previous chapters I conducted a meta-synthesis of the available literature to develop an understanding of what women experience at different stages of their hormonal treatment. The meta-synthesis models were then developed further after I conducted an interview study of my own. The ultimate goal of my study was always to try and look at the possibility of developing an intervention that could potentially improve women's experience of hormone therapy for the management of a breast cancer diagnosis and improve their adherence. The NICE recommendation for improving adherence is the following: "identification of specific perceptual and practical barriers to adherence for each individual, both at the time of prescribing and during regular review, because perceptions, practical problems and adherence may change over time" (NICE, 2009). My previous studies and the grounded theory I developed answer this recommendation perfectly by capturing women experiences while taking hormone therapy across the different phases of their treatment.

Another step to developing an intervention as recommended by NICE is to "establish the most effective way of communicating with each patient and, if necessary, consider ways of making information accessible and understandable (for example, using pictures, symbols, large print, different languages, an interpreter or a patient advocate)" (NICE, 2009). Again, this recommendation has been answered in this thesis by the pictograms I designed in Chapter 4 and finalised in Chapter 6 to make the grounded theory models more accessible and easier to understand. In this chapter I look at the possibility of using the pictograms to develop an educational tool to inform survivors and healthcare providers alike about the experiences of women on hormone therapy, with the goal of

improving women's experience of the treatment to potentially improve their adherence. The design of any intervention should take into consideration the NICE recommendation to "be aware that although adherence can be improved, no specific intervention can be recommended for all patients. Tailor any intervention to increase adherence to the specific difficulties with adherence the patient is experiencing." (NICE, 2009).

Behavioural change interventions are defined as "coordinated sets of activities designed to change specified behaviour patterns" (Michie et al., 2011). It has been shown that to improving the design and implementation of evidence-based practice depends on successful behavioural change interventions. This requires an appropriate method for characterizing interventions and linking them to an analysis of the target behaviour (Michie et al., 2011). In this final piece of research for my thesis I discuss the different theories of behavioural change and look at the possibility of developing behavioural change interventions using my findings.

7.2 Theories of behavioural change

Multiple theories have been advanced in the medical literature to explain human behaviour'. Some of the longstanding models of behavioural change are the health belief model (HBM), the social cognitive theory (SCT), the integrative model (IM), the transtheoretical model (TTM), the fuzzy-trace theory (FTT) and the temporal self-regulation theory (TST). In the next few paragraphs I will briefly describe each of these models.

The first is the health belief model (HBM), which is one of the most widely used models in health psychology (Donyai, 2012). The HBM assumes that people act the way they do because of their beliefs about the risk posed by a health problem and their perception of the benefits of taking a given preventative action (Donyai, 2012; Ogden, 2012). These two factors will determine their willingness to perform the desired behaviour. The core constructs of this model are presented in Figure 7-1 and include the perceived threat of the disease, the perceived benefits of the preventative action, the perceived barriers to taking the preventative action, the perceived susceptibility to the disease, the perceived seriousness of the disease, the cues for action (to promote the change in behaviour) and

self-efficacy (the control people have over performing the behaviour) (Donyai, 2012). The limitation of HBM is that it is reductionist in the fact that it does not take into account emotional factors such as fear and denial. Also, it solely focuses on the individual with complete disregard to social and economic factors (Ogden, 2012). Therefore, I considered this model unsuitable for the next phase of my study, based on my findings which did refer to social and economic factors.

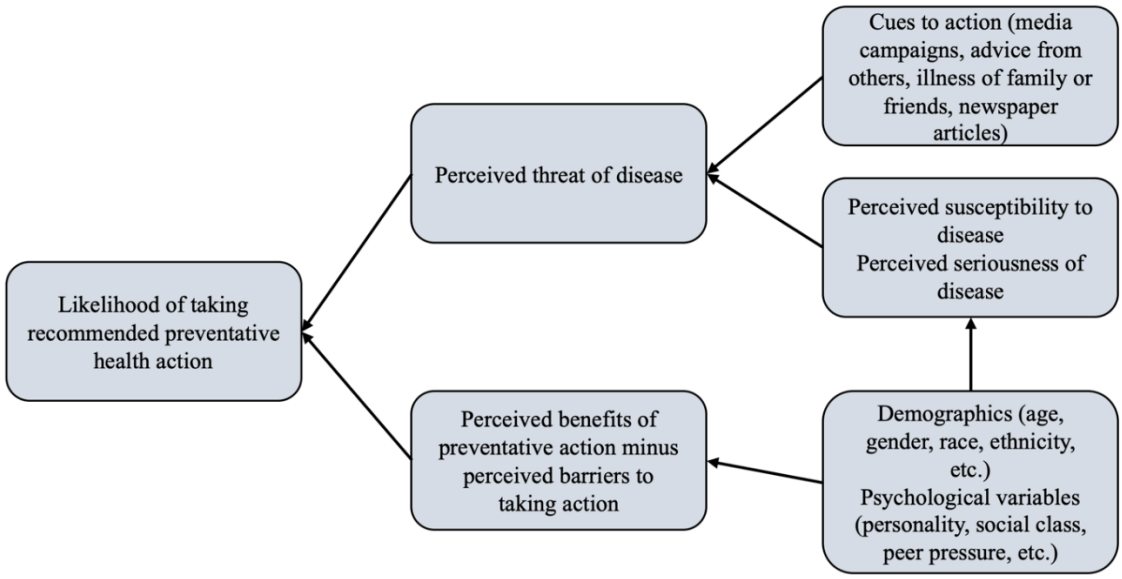


Figure 7-1: The health belief model (HBM), adapted from Donyai (2012).

The second model is the social cognitive theory (SCT). The assumption of SCT is that people act the way they do because of expectancies and incentives (Donyai, 2012). The core constructs of this theory and how they affect the individual's behaviour are presented in Figure 7-2 and include knowledge (risks and benefits of the healthy behaviour), perceived self-efficacy (control over habits), outcome expectancies (cost and benefits of different habits), health goals (plans and strategies) and perceived facilitators and constraints to change (Donyai, 2012). Similar to HBM, SCT fail in capturing the effect of emotional factors on people's behaviour. Also, it assumes that the changes to the environment will change the behaviour and this is not always true (Ogden, 2012). Therefore, again, I discounted this theory for my own study.

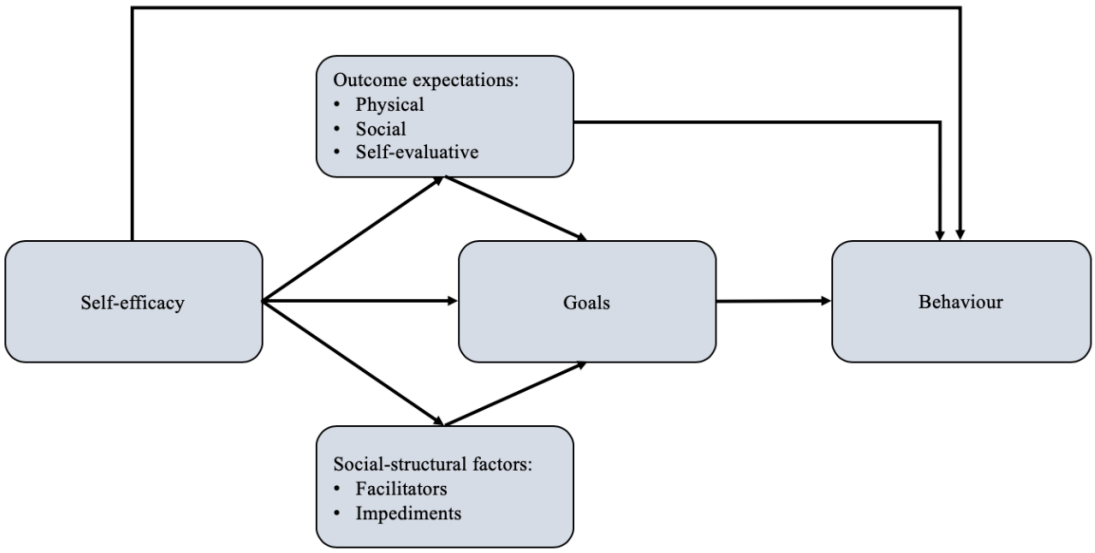


Figure 7-2: The social cognitive theory (SCT), adapted from Donyai (2012).

The third model is the integrative model (IM), which is the latest variation of the theory of reasoned action (TRA) and the theory of planned behaviour (TPB) (Glanz et al., 2015) (see Figure 7-3). TRA assumes that intention to perform a behaviour is the most determinant factor of behaviour and is influenced by attitudes and subjective norms. TPB adds perceived control as an extra factor that influences intention to perform a behaviour (Glanz et al., 2015; Ogden, 2012). IM is the latest variation of this model and contains constructs of both TRA and TPB. However, it adds other components that influence the behaviour directly (see Figure 7-4). The added components are the knowledge and skills to perform the behaviour, environmental constraints on performing the behaviour, the habits of the individual and the salience of the behaviour (Glanz et al., 2015). Despite TPB being a popular theory in health psychology, there have been some criticism about its predictive validity (Sniehotta et al., 2014). I personally felt that this theory despite being more inclusive than the previous ones was still too reductionist and not inclusive of all of my own findings.

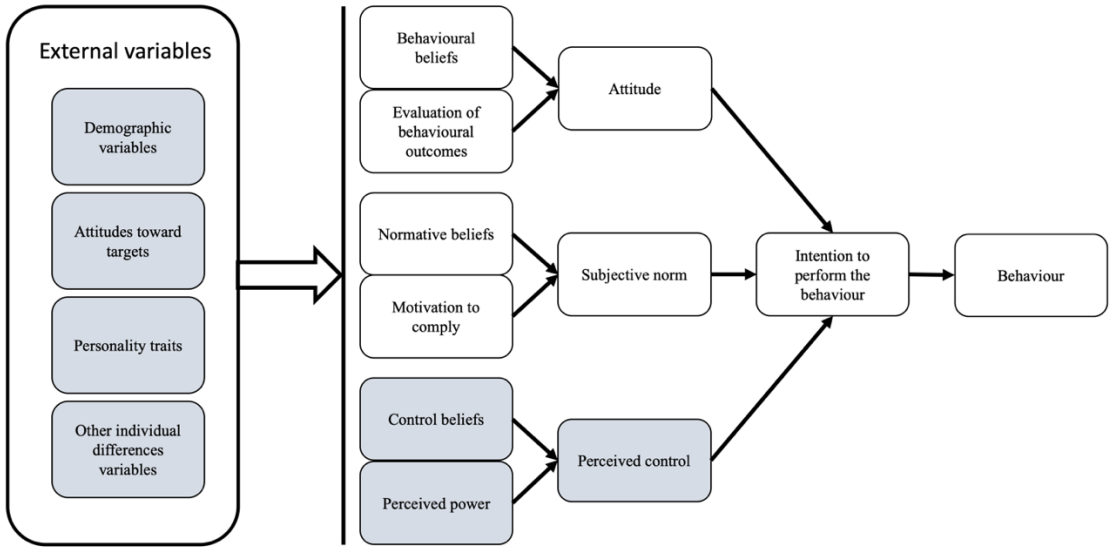


Figure 7-3: Theory of reasoned action (TRA) (upper light area) and the theory of planned behaviour (TPB) (entire figure), adapted from Glanz et al. (2015).

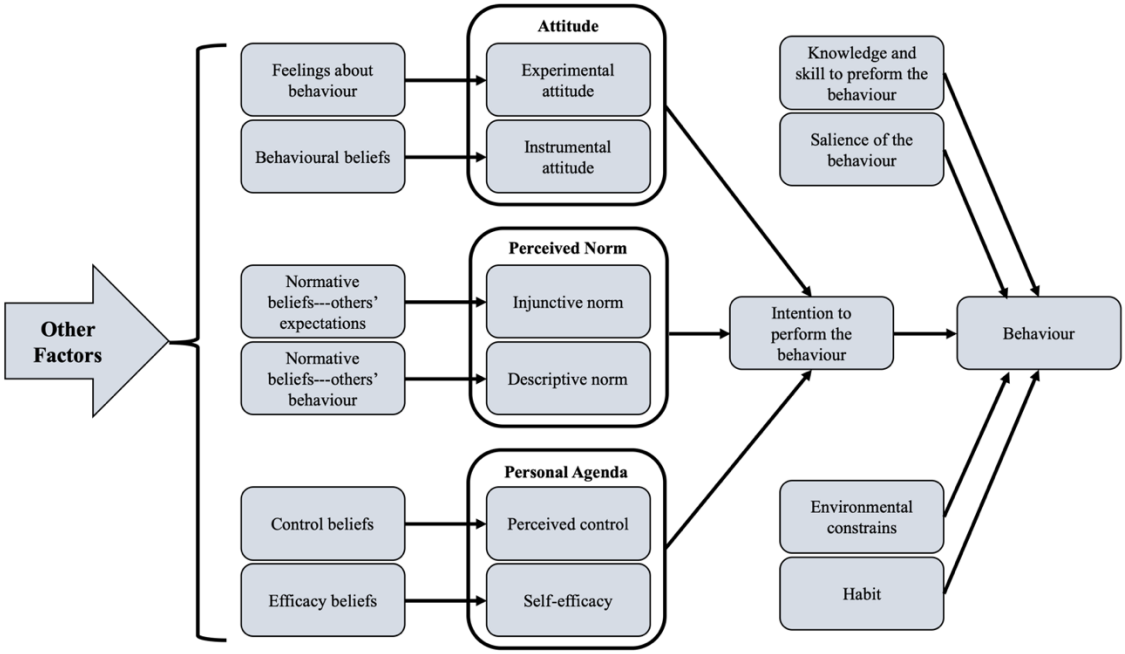


Figure 7-4: Integrative model (IM), adapted from Glanz et al. (2015).

The fourth model is the transtheoretical model (TTM). This model has the "stages of change at its core" and, instead of thinking of change as a sudden event, breaks down the process of change into different stages, as we can see in Figure 7-5 (Donyai, 2012). These stages are precontemplation (no intention to change the behaviour), contemplation (intention to change the behaviour), preparation (preparing to change the behaviour), action (changing the behaviour), maintenance (avoiding relapse to previous unhealthy behaviour) and termination (healthy behaviour is now the norm and there is no temptation to revert to the previous behaviour) (Donyai, 2012; Ogden, 2012). The problem with TTM is that it assumes that people make coherent and stable plans. Also, it assumes that the behaviour occur in multiple stages rather than a continuum (Ogden, 2012). This theory, again, did not capture the breadth of my findings..

Figure 7-5: Transtheoretical model (TTM), adapted from Donyai (2012).

The fifth model is the fuzzy-trace theory (FTT). Normative theories think of human behaviour as being characterized by the use of rationality to arrive at optimal decisions. However, this is not always the case, people sometimes acting in irrational ways which, however illogical, made perfect sense to them at the time (Donyai, 2012; Blalock and Reyna, 2016). The assumption of FTT is that to consider someone's judgment and decision-making process we must first consider the representation of information by the individual. The representation of information is divided into two types: gist representation and verbatim representation (Donyai, 2012; Blalock and Reyna, 2016). Gist representation is fuzzy and qualitative in nature and attempts to understand behaviour, however whimsical, by going straight to the heart of the matter. It is based on various factors, including emotion, education, culture, experiences and development level. Verbatim representation, by contrast, is exact and quantitative, attempting to capture the literal description of the behaviour. According to FTT, the mental representation of information as either gist or verbatim does not itself determine judgment or the decision-making process; rather it is the application of people's knowledge, principles and values that determines the decision, as can be seen in Figure 7-6 below

(Donyai, 2012). Although not sufficiently detailed otherwise, the idea of gist representation from the FTT matched the approach to represent information as pictograms.

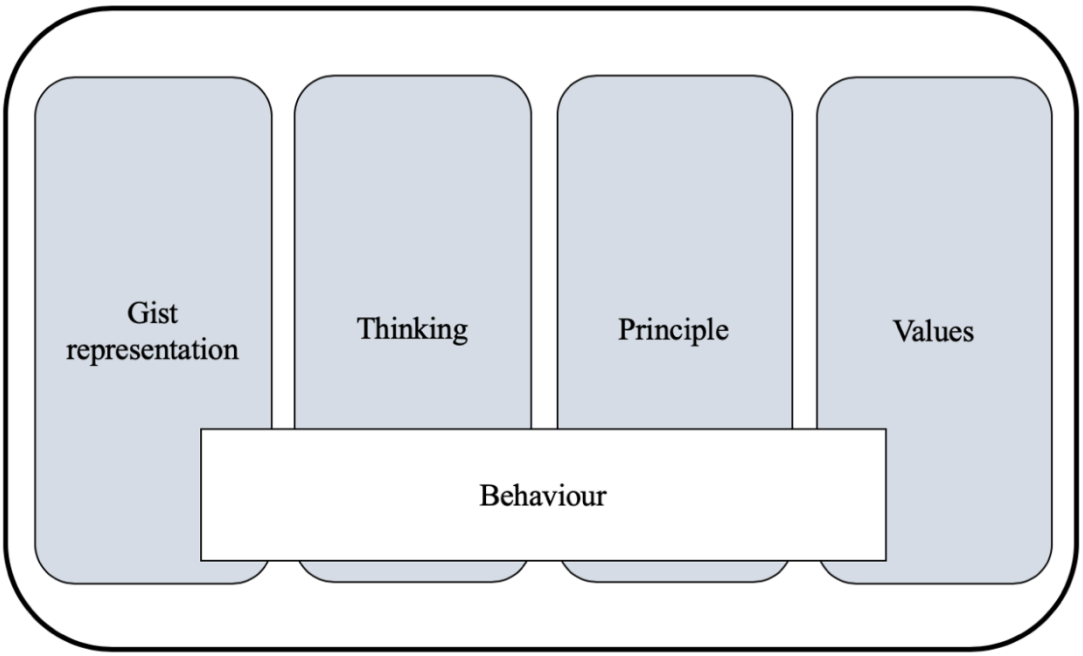


Figure 7-6: The fuzzy-trace theory (FTT), adapted from Donyai (2012).

The final model discussed here is the temporal self-regulation theory (TST). The assumption of TST is that the capacity of an individual to engage in a behaviour arises from a combination of biological factors (ex. physiological energy) and social cognitive factors that are divided into connectedness beliefs (beliefs about the relation between the behaviour and the eventual outcome) and temporal valuation (the time needed for reaching a different outcome (immediate versus non-immediate)) (Hall and Fong, 2007; Cameron, 2010). As seen in Figure 7-7, TST holds motivation to be a primary function of engaging in a behaviour. It also assumes that the intention to engage in a behaviour is controlled by behavioural pre-potency (a quantifiable value reflecting frequency of past performance and/or the presence of cues to action in the environment) and self-regulatory capacity (any state- or trait-like factor that affects an individual's capacity to effortfully regulate their own behaviour) (Hall and Fong, 2007). TST focuses on an individual's

decision making process, making this focus again too reductionist and unsuitable for the next stage of research.

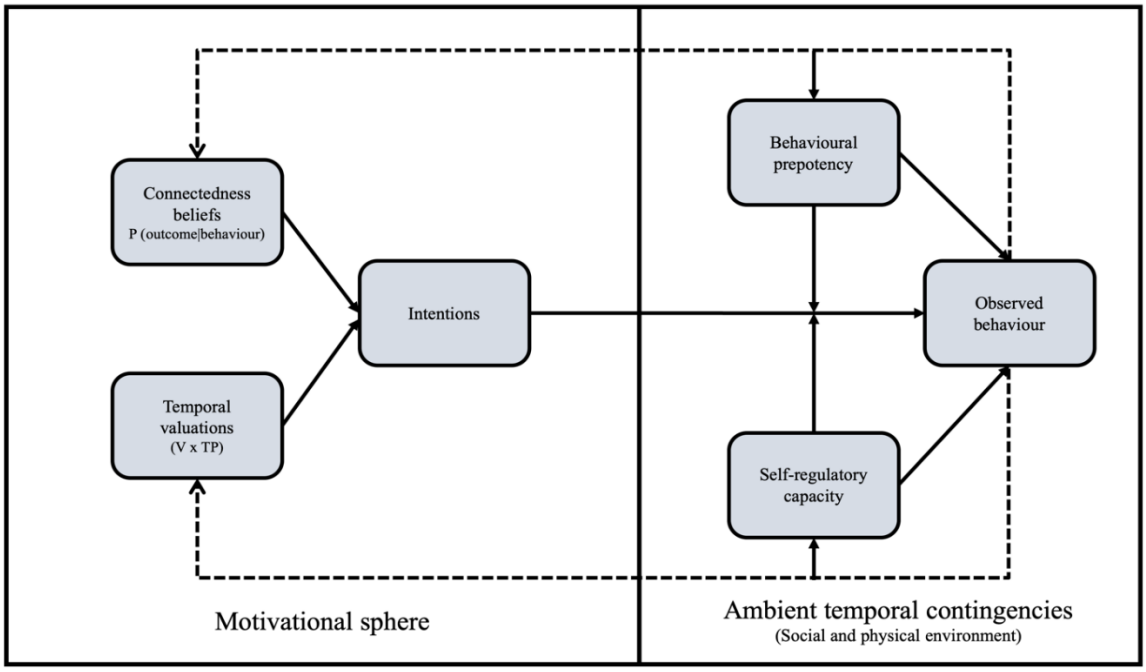


Figure 7-7: The temporal self-regulation theory (TST), adapted from Hall and Fong (2007).

7.2.1 The theoretical domain framework (TDF)

By choosing one of the theories described above as the basis of intervention development, I would be faced with two issues. The first would be the risk of missing out on important theoretical constructs that the one chosen theory lacks. The second would be having to force the data into an unrelated theoretical construct that the theory includes. Choosing one of the previous theories appeared too reductionist and somewhat ironic, since I had completed a qualitative study which examined and detailed complexity rather than simplicity and reduction. Women's adherence to hormone therapy is a complex behaviour as I have shown in previous chapters. The distillation needed to fit this phenomenon into one of the models I described above would have affected the intricacy and richness of my findings. To minimise this risk, I started looking at integrated models and I came across the theoretical domain framework (TDF) which I decided to implement. TDF is an integrative framework of behavioural change theories that was developed by simplifying and integrating multiple behavioural change theories to construct a single theory that is both more accessible and easier to understand and implement by different disciplines (Michie et al., 2005). TDF was developed with the input of 18 psychological theorists, 16 health service researchers and 30 health psychologists. This group of researchers were able to find 33 health psychological theories and extract a total of 128 theoretical constructs (Michie et al., 2005). These were then summarized into 12 theoretical domains that were revised and refined, ultimately comprising a total of 14 different domains (Cane et al., 2012). These domains are 1) knowledge, 2) skills, 3) social/professional role and identity, 4) beliefs about capabilities, 5) optimism, 6) beliefs about consequences, 7) reinforcement, 8) intentions, 9) goals, 10) memory, attention and decision processes, 11) environment context and resources, 12) social influences, 13) emotion and 14) behavioural regulation; see Table 7-1 (Cane et al., 2012). The use of TDF offered multiple key advantages over other theories. First, it offers a comprehensive coverage of possible influences on the behaviour. Second, each domain is clearly defined and offers a clear description of its influence. Third and most importantly, it offers a link between theories of behavioural change and techniques of behavioural change to address implementation issues.

Table 7-1: The TDF domains and definitions, adapted from Phillips et al. (2015).

TDF domain	Definition
Knowledge	An awareness of the existence of something
Skills	An ability or proficiency acquired through practice
Social/professional role and identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting
Beliefs about capabilities	Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use
Optimism	The confidence that things will happen for the best, or that desired goals will be attained
Beliefs about consequences	Acceptance of the truth, reality or validity about outcomes of a behaviour in a given situation
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus
Intentions	A conscious decision to perform a behaviour or a resolve to act in a certain way
Goals	Mental representation of outcomes or end states that an individual wants to achieve
Memory, attention and decision processes	The ability to retain information, focus selectively on aspects of the environment, and choose between two or more alternatives
Environmental context and resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour
Social influences	Those interpersonal processes that can cause an individual to change their thoughts, feelings or behaviours
Emotion	A complex reaction pattern, involving experiential, behavioural and physiological elements, by which the individual attempts to deal with a personally significant matter or event
Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions

7.2.2 The COM-B model

In designing interventions, TDF fits well with the capability, opportunity and motivation model of behaviour (COM-B) and the behavioural change wheel (BCW), which I discuss below. COM-B is a psychological model attempting to capture a wide range of mechanisms that are involved in changing a behaviour (Michie et al., 2011). Definitions of this system's three components and their six sub-components can be found in Table 7-2. The idea of the COM-B model is that any behaviour consists of an interaction between capability, opportunity and motivation. To develop an intervention, one must change one of the components of this model in order to also change the interaction between the various components and produce a new behaviour (Michie et al., 2011). By changing opportunity, motivation is affected, and both alter the behaviour. Similarly, by

changing the capability, motivation is affected, and both alter the behaviour. Also, forcing a change in the behaviour itself will alter all three components and put the whole system into a new configuration (Michie et al., 2011). Figure 7-8 shows the possible interactions between the various components of the model.

Table 7-2: COM-B components and sub-components with their definitions (Michie et al., 2011)

COM-B main components	Definition	COM-B sub-components	Definition
Capability	The individual's psychological and physical capacity to engage in the behaviour	**Psychological**	Capacity to engage in necessary thought processes
		Physical	Capacity to engage in necessary physical processes
Motivation	All brain processes that energize and direct the behaviour	**Reflective**	Evaluations and plans
		Automatic	Emotions and impulses arising from associative learning and/or innate dispositions
Opportunity	All factors lying outside the individual that make performance of the behaviour possible or prompt it	**Physical**	Physical opportunity provided by the environment
		Social	Cultural milieu that dictates the way we think about things

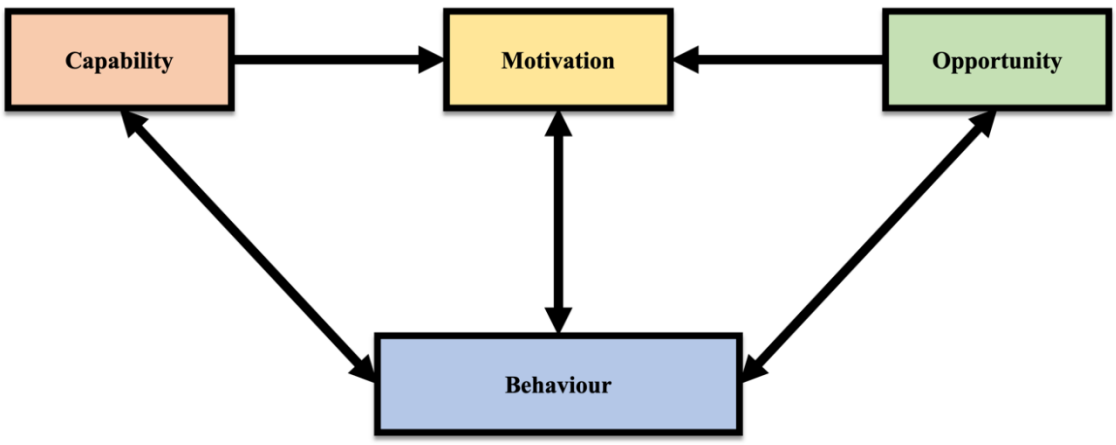


Figure 7-8: The COM-B model of behaviour (Michie et al., 2011).

With the help of three experts in behavioural change, the domains of the TDF have been mapped into the components of the COM-B model with 100% agreement, as shown in Table 7-3 below. By including this step, the COM-B model has helped researchers to identify the domains of TDF that are important in changing the behaviour, and intervention designers to know what domains to tackle to inform the choice of an intervention (Cane et al., 2012).

Table 7-3: Mapping of the COM-B model of behavioural change to TDF domains (Cane et al., 2012).

COM-B main components	COM-B sub-components	TDF domains
Capability	**Psychological**	Knowledge Cognitive and interpersonal skills Memory, attention and decision processes Behavioural regulation
	Physical	Physical skills
Motivation	**Reflective**	Professional/social role and identity Beliefs about capabilities Optimism Beliefs about consequences Intentions Goals
	Automatic	Reinforcement Emotion
Opportunity	**Physical**	Environmental context and resources
	Social	Social influences

7.2.3 The COM-B model and medication adherence

In 2014, Jackson et al. (2014) published a paper applying the COM-B model to tackling the issue of medication adherence; see Figure 7-9. They represented the issue of adherence as a continuum, hence the double-edged arrows. They then tried to identify all factors associated with medication non-adherence by extracting factors from Pound et al. (2005), and NICE (2009) and the 461 factors reported by Kardas et al. (2013). Finally, they examined these issues and agreed on a final list of common factors and how they map to the COM-B model, as seen in Table 7-4.

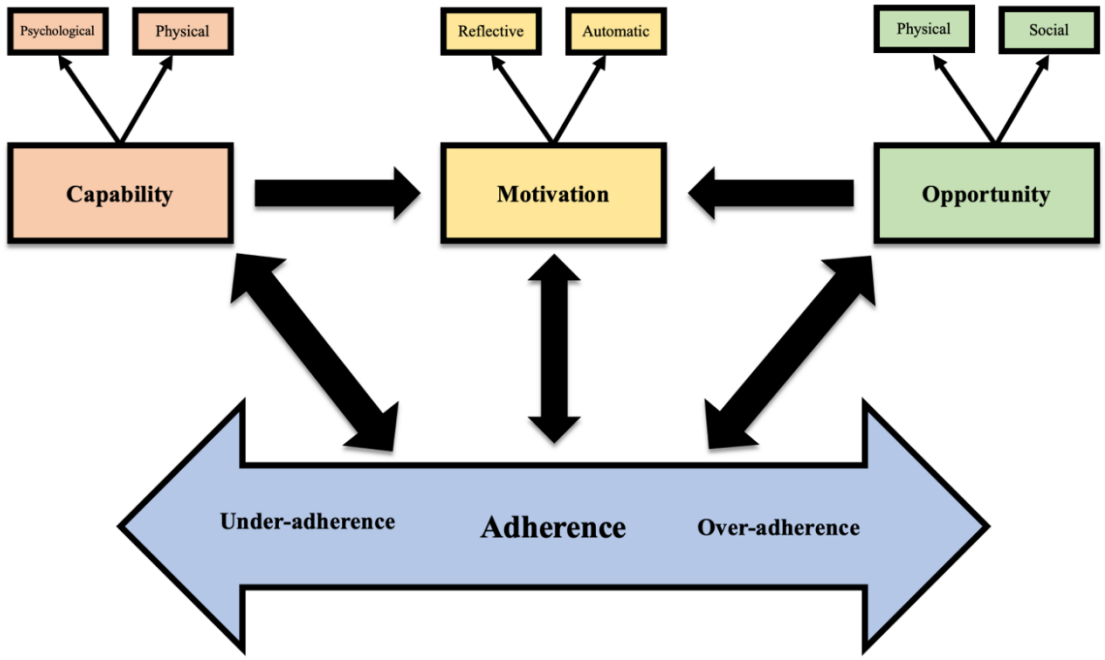


Figure 7-9: The application of COM-B to adherence (Jackson et al., 2014).

Table 7-4: Mapping of the COM-B model of behavioural change to TDF domains and the factors associated with adherence (Jackson et al., 2014).

COM-B main components	COM-B sub-components	TDF domains	Factors associated with adherence
Capability	**Psychological**	Knowledge Cognitive and interpersonal skills Memory, attention and decision processes Behavioural regulation	Comprehension of disease and treatment Cognitive functioning (e.g. memory, capacity for judgment, thinking) Executive function (e.g. capacity to plan)
	Physical	Physical skills	Physical capability to adapt to lifestyle changes (e.g. diet or social behaviours) Dexterity
Motivation	**Reflective**	Professional/social role and identity Beliefs about capabilities Optimism Beliefs about consequences Intentions Goals	Perception of illness (e.g. cause, chronic vs, acute, etc.) Beliefs about treatment (e.g. necessity, efficacy, concerns about current or future adverse events, general aversion to taking medicines) Outcome expectations Self-efficacy
	Automatic	Reinforcement Emotion	Stimuli or cues for action Mood state/disorder (e.g. depression and anxiety)
Opportunity	**Physical**	Environmental context and resources	Cost Access (e.g. availability of medication) Packaging Physical characteristics of medicine (e.g. taste, smell, size, shape, route of administration) Regimen complexity Social support HCP-patient relationship/communication
	Social	Social influences	Stigma of disease, fear of disclosure Religious/cultural beliefs

7.2.4 Experiences from the grounded theory models in relation to the COM-B model components and the factors associated with adherence

I examined the categories from my own study. Using the COM-B model, the TDF and the factors associated with adherence, I began by classifying my own categories to the sub-component of the COM-B model by cross-matching them. For example, comprehension of disease and treatment is a factor associated with adherence that falls underneath the COM-B component psychological capability. From my own findings the following experiences also fall underneath this factor; being overwhelmed by the received information, lack of information about the treatment and lack of understanding of the provided information. Another example from the original COM-B model is physical capability to adapt to lifestyle changes, which from my own study include; ability to adapt to taking the treatment and the side-effects, ability to adapt to changes to the usual routine, ability to adapt to taking care of oneself, and ability to ask for help. I completed this cross-matching for all the categories identified in my grounded theory studies and these are presented in Table 7-5 and Figure 7-10 below.

Table 7-5: Breast cancer survivors' experiences from the grounded theory models in relation to the COM-B model components and the factors associated with adherence.

COM-B components	Factors associated with adherence according to Jackson et al (2014).	Evidence from my grounded theory study
Psychological capability	Comprehension of disease and treatment Cognitive functioning (e.g. memory, capacity for judgment, thinking) Executive function (e.g. capacity to plan)	Transition into a new stage of treatment Being overwhelmed by the received information Lack of information about the treatment Lack of understanding of the provided information Ability to find the correct information Need of knowledge vs. preference of ignorance Ability to remember to take the treatment Remembering to fill in the prescription Having other priorities Working out the bureaucracy in the healthcare system Uncertainty about reaching the end of the treatment
Physical capability	Physical capability to adapt to lifestyle changes (e.g. diet or social behaviours) Dexterity	Ability to adapt to taking the treatment and the side-effects Ability to adapt to changes to the usual routine Ability to adapt to taking care of oneself Ability to ask for help
Reflective motivation	Perception of illness (e.g. cause, chronic vs. acute, etc.) Beliefs about treatment (e.g. necessity, efficacy, concerns about current or future adverse events, general aversion to taking medicines) Outcome expectations Self-efficacy	Perception of the treatment (positive or negative) Severity of the side-effects of the treatment Trust in the treatment and its necessity Uncertainty about the treatment Fear of recurrence Fear of side-effects Wanting to continue living cancer-free Owing it to everyone involved
Automatic motivation	Stimuli or cues for action Mood state/disorder (e.g. depression and anxiety)	Experiencing difficulties during the initial stage of the treatment Continuing to feel as a cancer patient Vulnerability
Physical opportunity	Cost Access (e.g. availability of medication) Packaging Physical characteristics of medicine (e.g. taste, smell, size, shape, route of administration) Regimen complexity Social support HCP-patient relationship/communication	Ease of access and availability of professional support Receiving the correct information Relationship with healthcare provider Support from family, friends, co-workers and other patients Expense of the treatment (insurance) Communication between different health sectors Limits of healthcare providers' knowledge
Social opportunity	Stigma of disease, fear of disclosure Religious/cultural beliefs	Faith and religion Discussing cancer (taboo or acceptable?)

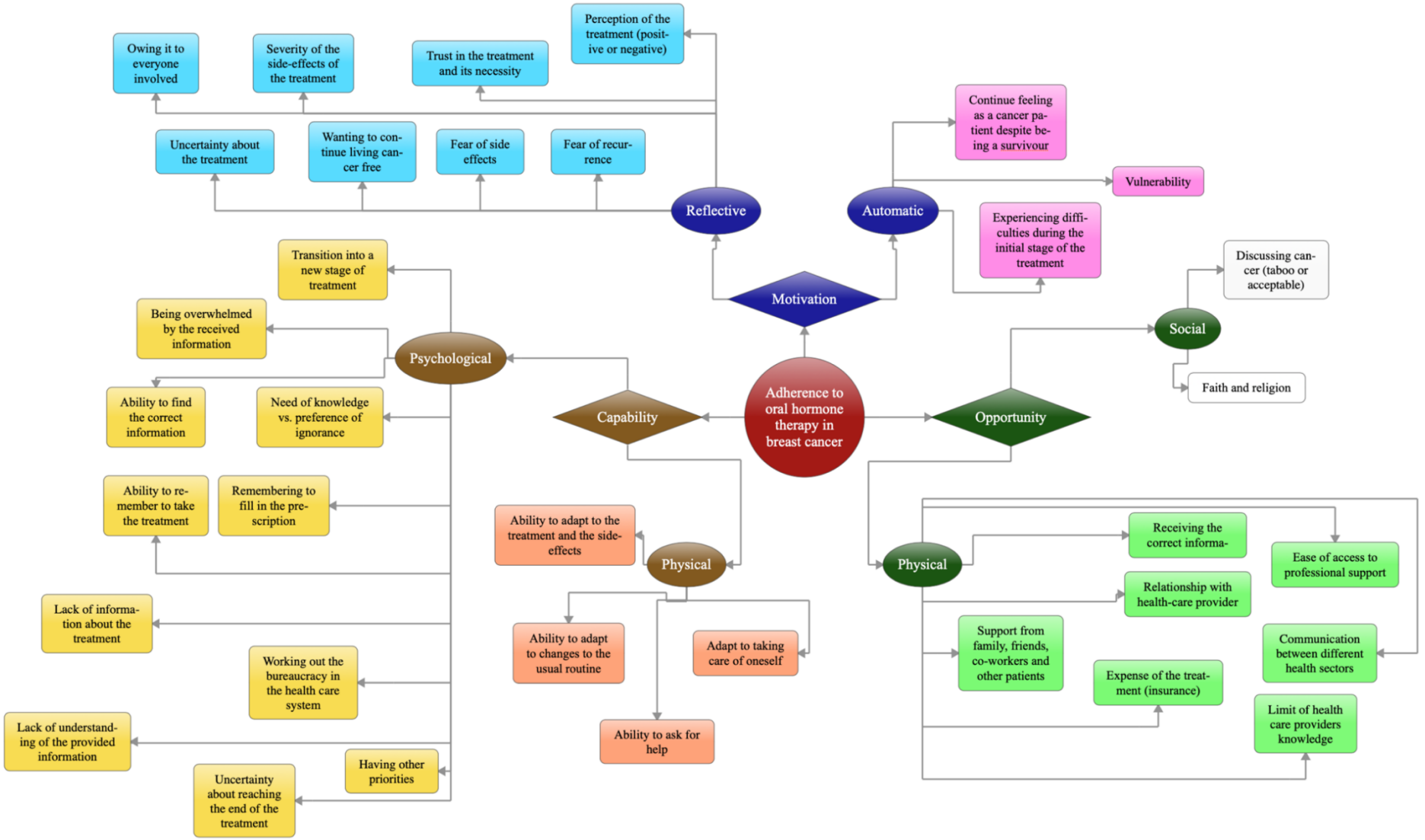


Figure 7-10: The categories of the grounded theory study and how they relate to the COM-B model.

7.2.5 The behavioural change wheel (BCW)

The last step of intervention development in my study related to the use of BCW to identify intervention functions for changing a behaviour. The COM-B model authors had conducted a systematic review of behavioural change interventions and found a total of nine intervention functions and seven policy categories, as seen in Table 7-6 below. These intervention and policies had also been integrated with the COM-B model to produce a new behavioural change system called the behavioural change wheel (BCW) (Michie et al., 2011). The BCW consists of the COM-B model components and sub-components at the middle of the system, surrounded by the nine intervention functions, which are then surrounded by the policy categories (Figure 7-11).

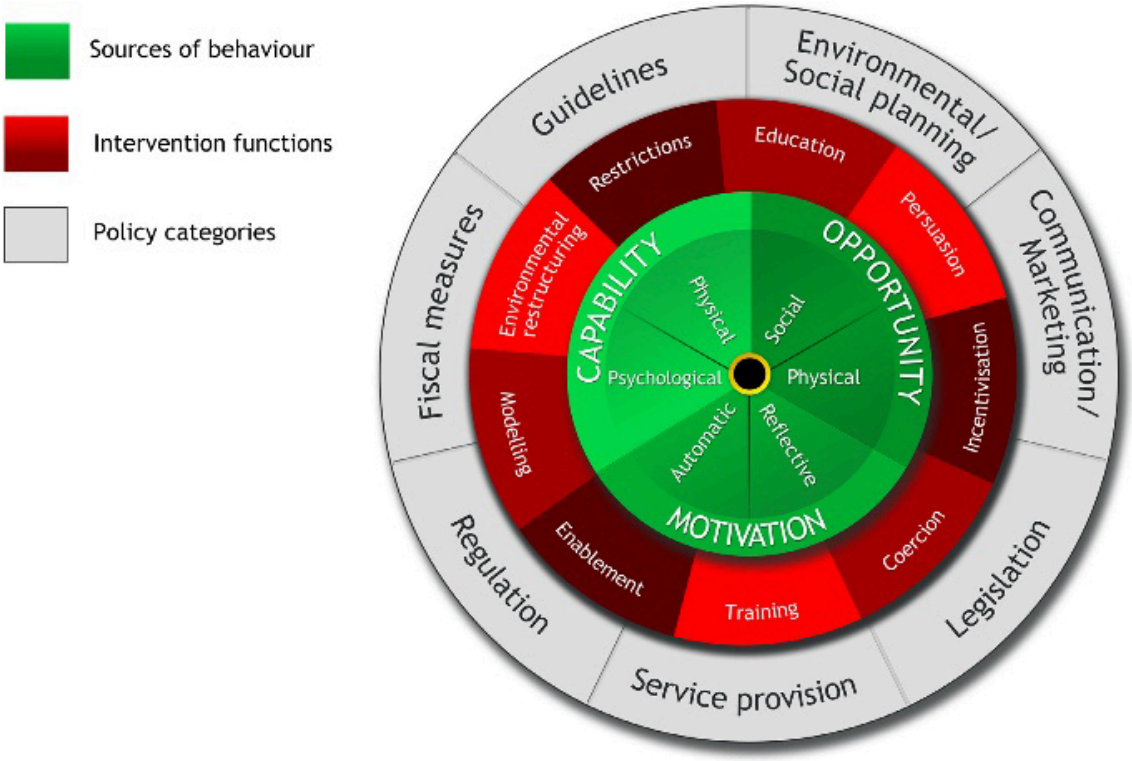


Figure 7-11: The behavioural change wheel, adapted from Michie et al. (2011).

The way this system works is by first classifying the behaviour that needs addressing, using the COM-B model, then identifying the intervention function that helps target the COM-B sub-components and thus assists in changing that behaviour. Table 7-7 below shows a matrix capturing the links between the COM-B components and sub-components and the intervention functions. For example, if I want to develop an intervention for an experience that falls underneath the COM-B sub-component psychological capability, the intervention functions I need to tackle are; education, training or enablement. While if I want to design an intervention for an experience that falls under physical capability, the intervention should either be training or enablement, and so on. It is worth mentioning that the BCW presented in Figure 7-11 is interactive. As it currently stands in the figure above, the wheel configuration does not match the COM-B component and the intervention function related to it correctly – thus it is Table 7-7 that is used for intervention identification rather than the static figure shown in Figure 7-11.

Intervention functions related to the COM-B model are education, persuasion, incentivization, coercion, training, restriction, environmental restructuring, modelling and enablement. Definitions of each of these intervention functions are presented in Table 7-6 below with an example that matches each function. These examples help in understanding how each intervention function could be tackled when developing an intervention of my own. The next step of intervention design is to match intervention functions with the experience related to it from the grounded theory models created in this thesis.

Table 7-6 Definitions of interventions and policies, adapted from Michie et al. (2011).

Intervention functions	Definition	Example
Education	Increasing knowledge or understanding	Providing information to promote healthy eating
Persuasion	Using communication to induce positive or negative feelings or stimulate action	Using imagery to motivate increases in physical activity
Incentivization	Creating expectation of reward	Using prize draws to induce attempts to stop smoking
Coercion	Creating expectation of punishment or cost	Raising the financial cost to reduce excessive alcohol consumption
Training	Imparting skills	Advanced driver training to increase safe driving
Restriction	Using rules to reduce the opportunity to engage in the target behaviour (or to increase the target behaviour by reducing the opportunity to engage in competing behaviours)	Prohibiting sales of solvents to people under 18 to reduce use for intoxication
Environmental restructuring	Changing the physical or social context	Providing on-screen prompts for GPs to ask about smoking behaviour
Modelling	Providing an example for people to aspire to or imitate	Using TV drama scenes involving safe-sex practices to increase condom use
Enablement	Increasing means/reducing barriers to increase capability or opportunity	Behavioural support for smoking cessation, medication for cognitive deficits, surgery to reduce obesity, prostheses to promote physical activity
Policies	**Definitions**	**Examples**
Communication/Marketing	Using print, electronic, telephonic or broadcast media	Conducting mass media campaigns
Guidelines	Creating documents that recommend or mandate practice. This includes all changes to service provision	Producing and disseminating treatment protocols
Fiscal	Using the tax system to reduce or increase the financial cost	Increasing duty or increasing anti-smuggling activities
Regulation	Establishing rules or principles of behaviour or practice	Establishing voluntary agreements on advertising
Legislation	Making or changing laws	Prohibiting sale or use
Environmental/Social planning	Designing and/or controlling the physical or social environment	Using town planning
Service provision	Delivering a service	Establishing support services in workplaces, communities, etc.

Table 7-7: Matrix of links between COM-B components and intervention functions, adapted from Michie et al. (2014).

COM-B components	Intervention functions								
	Education	Persuasion	Incentivization	Coercion	Training	Restriction	Environmental restriction	Modelling	Enablement
Psychological capability	✓				✓				✓
Physical capability					✓				✓
Reflective motivation	✓	✓	✓	✓					
Automatic motivation		✓	✓	✓	✓		✓	✓	✓
Physical opportunity					✓	✓	✓		✓
Social opportunity						✓	✓	✓	✓

7.3 Applying the COM-B model, the TDF and BCW to the categories of my grounded theory studies

My aim was to develop possible interventions to help with adherence to hormonal medication in breast cancer survivorship. Using the COM-B model, the TDF and the factors associated with adherence, I was able to map the categories from my own study to the sub-components of the COM-B model. By using the BCW, I mapped the intervention function next to every category from my own study. I then thought through and identified possible interventions that could be associated with each separate category matching the intervention function it is connected to and then checked my thoughts with my primary supervisor (see Figure 7-12). This systematic way of classifying and brainstorming resulted in the development of a long list of possible interventions which I have presented as Table 7-8 below.

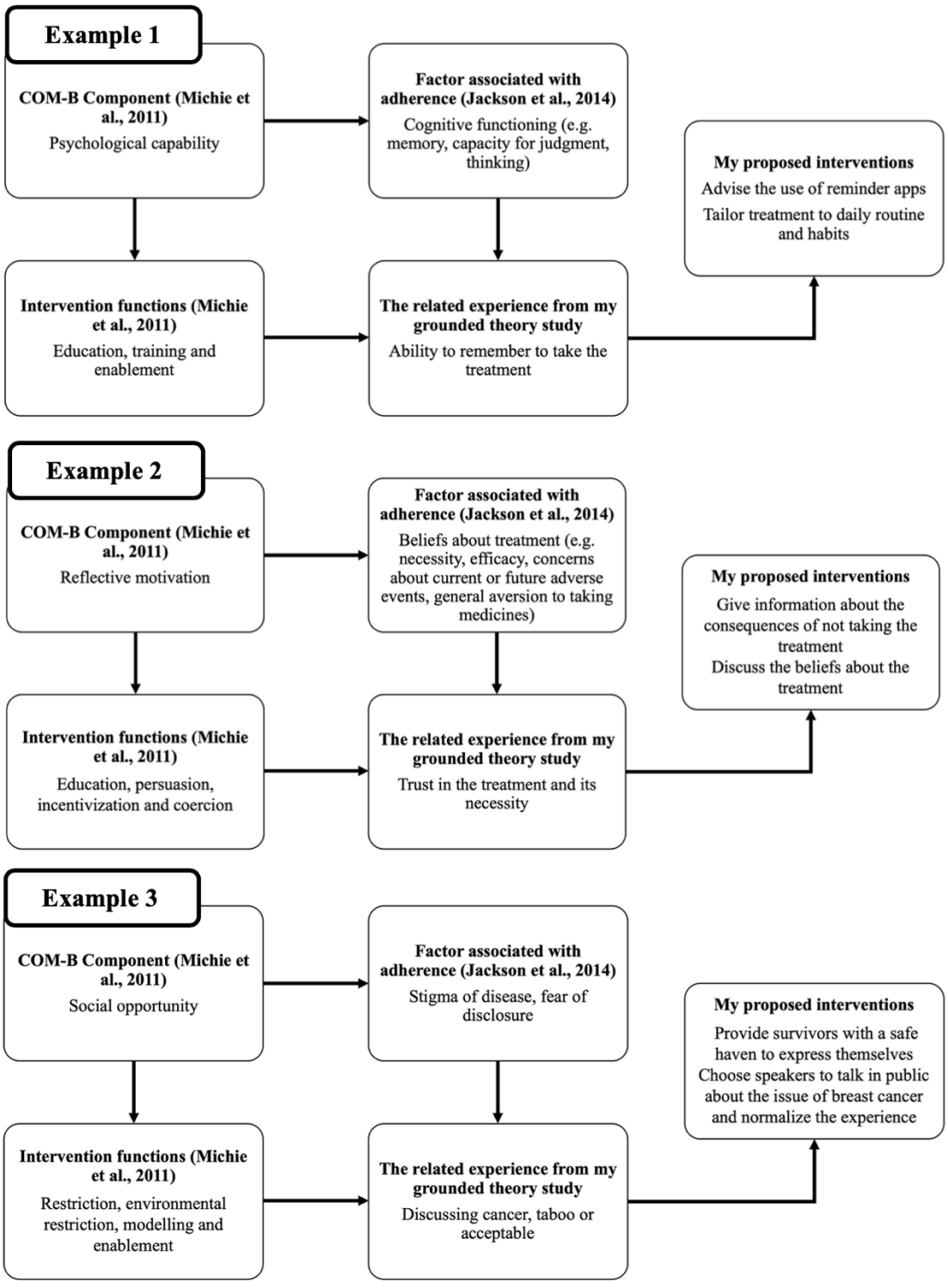


Figure 7-12: Three examples of the step-by-step intervention development.

Table 7-8: Breast cancer survivors' negative experiences from the grounded theory models in relation to the COM-B model and the possible intervention based on the matching intervention functions from the BCW.

COM-B components	Intervention functions	Experiences	Intervention
Psychological capability	**Education Training Enablement**	Transition into a new stage of treatment	Provide information about what to expect during the treatment and a list of organizations that could offer help and support
		Being overwhelmed by the received information	Provide the information gradually Share a set of reliable websites that provide the patients with information at their own pace and preference
		Lack of information about the treatment	Share support groups and support organization that could offer the information Share a set of reliable websites
		Lack of understanding of the provided information	Share support groups and support organization that could offer the information Share a set of reliable websites that speak to low health literacy patients Ask women to repeat information
		Ability to find the correct information	Share a set of reliable websites that provide accurate information Share a set of updated flayers
		Need of knowledge vs. preference of ignorance	Share a set of reliable websites so patients can learn at their own pace and preference
		Ability to remember to take the treatment	Advise the use of reminder apps Tailor treatment to daily routine and habits
		Remembering to fill in the prescription	Advise the use of reminder apps Pharmacy sent reminders
		Having other priorities	Provide information about the importance of adherence Provide information about the consequences of non-adherence
		Working out the bureaucracy in the healthcare system	Provide information about what to expect during the treatment and a list of organizations that could offer help and support Provide survivors with a list of important dates and milestones in advance
		Uncertainty about reaching the end of the treatment	Provide survivors with a list of important dates and milestones in advance

Physical capability	**Training Enablement**	Ability to adapt to taking the treatment and the side-effects	Share examples of multiple others' experiences Change the time of taking the treatment
		Ability to adapt to changes to the usual routine	Tailor treatment to daily habits Advise the use of reminder apps
		Adapt to taking care of ones-self	Share examples of others' experiences Provide counselling about lifestyle changes
		Ability to ask for help	Provide women with a list of support organizations Ensure women that offering help is part of the job description
Reflective motivation	**Education Persuasion Incentivization Coercion**	Perception of the treatment (positive or negative)	Discuss beliefs about the treatment Share a set of reliable websites that provide accurate information
		Severity of the side-effects of the treatment	Share examples of others' experiences Change medication taking time Use a different brand of the treatment Take other treatment to manage side-effects Change the treatment
		Trust in the treatment and its necessity	Give information about the consequences of not taking the treatment Discuss the beliefs about the treatment
		Uncertainty about the treatment	Discuss beliefs about the treatment Give information about the consequences of not taking the treatment
		Fear of recurrence	Share examples of others' positive experiences
		Fear of side-effects	Share examples of others' positive experiences
		Wanting to continue living cancer-free	Provide information about the importance of taking the treatment to prevent recurrence
		Owing it to everyone involved	Advise patients to think of their family and how their decision might affect them
Automatic motivation	**Persuasion Incentivization Coercion Training**	Experiencing difficulties during the initial stage of the treatment	Give information about a self-help group that offers support for the behaviour Provide examples of people who have gone through a similar situation

	Environmental restriction Modelling Enablement	Continue feeling as a cancer patient	Assure women that they are cancer-free Empower women to take control of their life
		Vulnerability	Empower women to take control of their life Provide examples of other women successfully going through a similar path
Physical opportunity	**Training Restriction Environmental restriction Enablement**	Ease of access to professional support	Provide a list of healthcare providers' contact information Healthcare system changes
		Receiving the correct information	Have a set of reliable websites that are updated with the latest information and are easy to comprehend and navigate
		Relationship with healthcare provider	Organize appointments with the same healthcare provider
		Support from family, friends, co-workers and other patients	Provide with list of support groups and support organizations that could offer help Advice on asking help from friends and family members
		Expense of the treatment (insurance)	List of financial support organizations List of charities Provide access to government-supported hospitals
		Communication between different health sectors	Establish a line of communication between specialists and general practitioners Healthcare system changes
		Limit of healthcare providers' knowledge	Educate healthcare providers about the treatment and its side-effects to be able to provide patients with the information they require Conduct more research on unknown issues
Social opportunity	**Restriction Environmental restriction Modelling Enablement**	Faith and religion	Use religious clerics of different religions to answer survivors' misconceptions about religion and modern medicine
		Discussing cancer, taboo or acceptable	Provide survivors with a safe haven to express themselves Choose speakers to talk in public about the issue of breast cancer and normalize the experience

7.4 Mode of intervention delivery

The next step was to establish possible methods of delivering the suggested interventions both to healthcare providers and breast cancer survivors. The methods of delivery arrived at were: interactive posters (with//without near field communication (NFC) tags, which could be programmed to perform specific tasks such as; opening a web page or a phone application just by tapping the device against the tag), a deck of interactive cards (with/without NFC tags), a phone application and an interactive website.

7.4.1 Interactive posters (with/without NFC tags)

The first design idea I have is to use the final set of pictogram models I had created and present it in the form of a poster. Breast cancer survivors who identify with the experience in the pictogram, then turn the specific pictogram of their experience over to see a suggested intervention to improve their experience. This could be improved by installing an NFC chip in each picture. When breast cancer survivors go through a negative experience they want to improve, they could bring the poster and scan the picture representing their experience with an NFC-ready device. This would take them to a website conveying the suggested intervention. Such posters could also be used by healthcare providers during consultations to establish ground for communication. A simplified example of an interactive poster is presented in Figure 7-13.

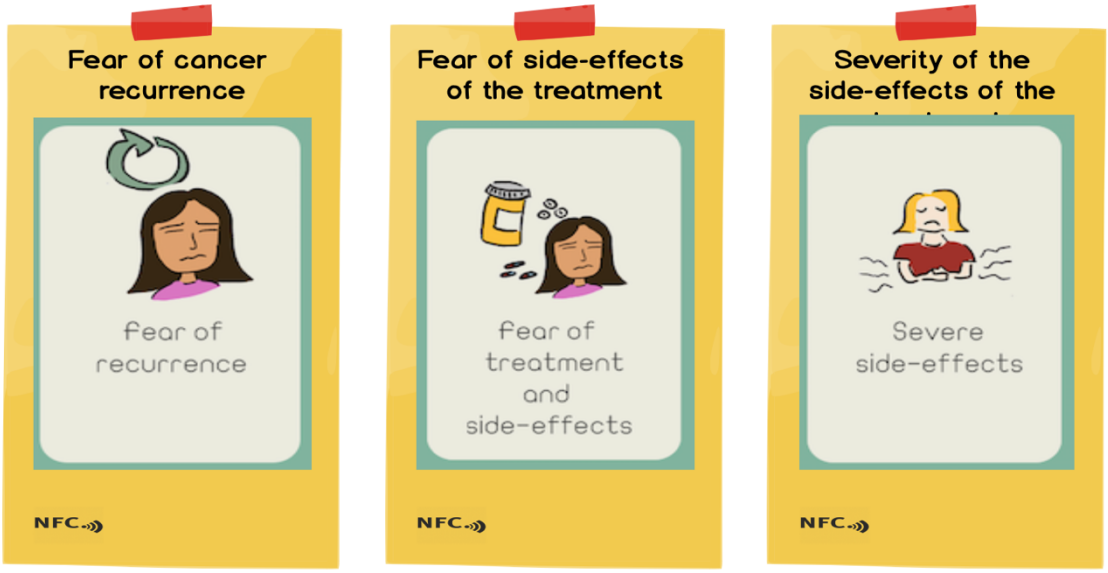


Figure 7-13: A simplified example of an interactive poster, showing the NFC tags on the bottom of each pictogram.

7.4.2 A deck of interactive cards (with/without NFC tags)

The second design idea is to turn the pictogram model of experiences into a set of cards. Women upon identifying with the experience on the card could then turn it over to read the suggested intervention / support to improve their experience. Similar to the poster idea above, this could be improved by installing an NFC chip in each experience card. When breast cancer survivors go through a negative experience they want to deal with, they could scan the card representing their experience with an NFC-ready device. This could take them to a website conveying the suggested intervention. These cards could also be used by healthcare providers in helping survivors explain what they are going through, in order to be able to provide them with the help they need. A simplified example of what a card intended for health professionals' use might look like is presented in Figure 7-14.

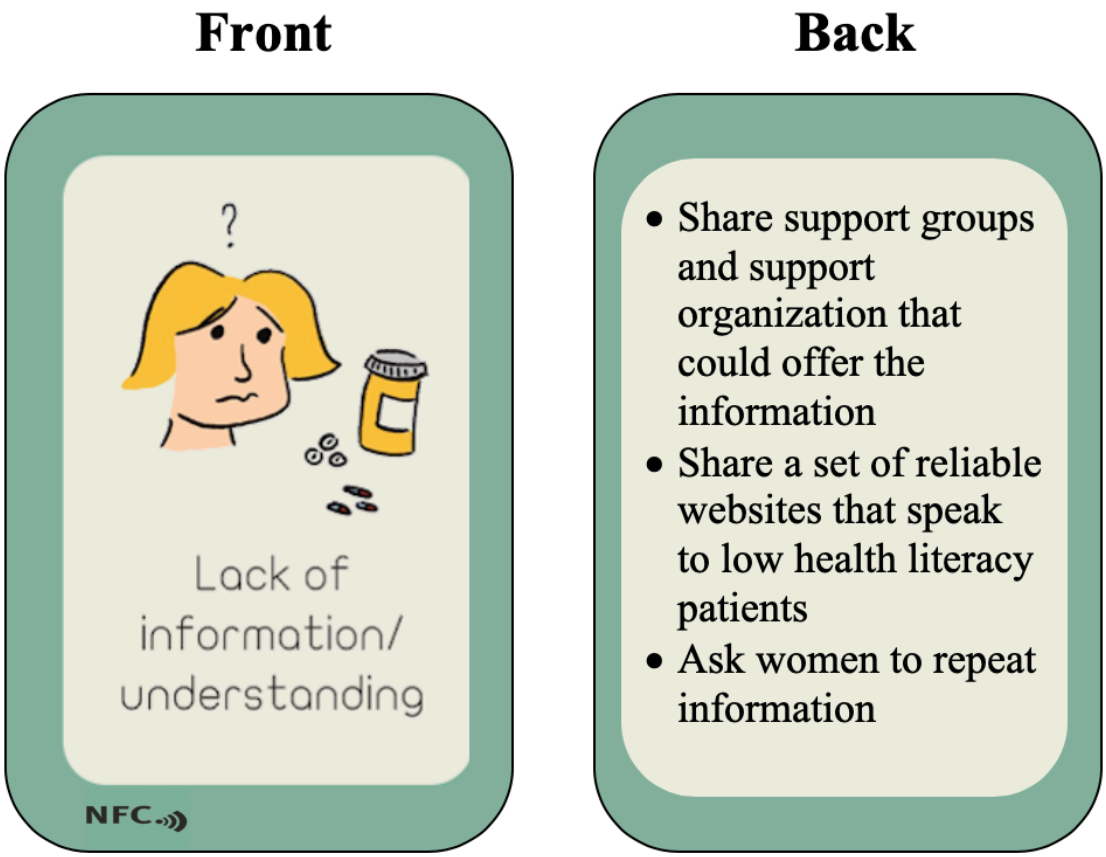


Figure 7-14: An example of a card from the front and back, showing the NFC tag on the bottom of the front face.

7.4.3 Phone application

My third idea is to design a phone application that breast cancer survivors could download to their phones. They could download the app, open it, choose the stage they are in from the three pictogram models and choose the experience they want to improve or learn more about. They would then be presented with a list of ideas / interventions they could pursue. The app could be downloaded by both survivors and healthcare providers and used by them during consultation visits (see Figure 7-15). In the first picture of the figure below, breast cancer survivors would choose the stage of their treatment. This will take them to the second picture, where they will be presented with the experiences related to their stage. When they choose the experience they are going through, they will be taken to the third picture where they will be presented with a list of suggested interventions – please note that the current language of the 'intervention' would be modified for patient use.

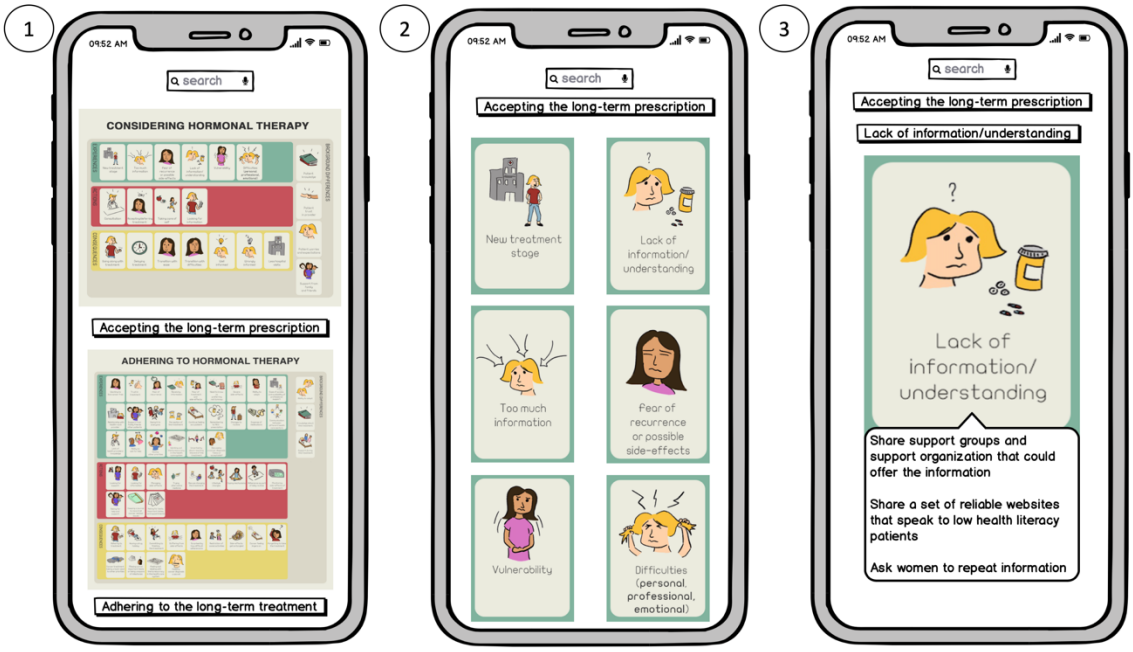


Figure 7-15: A simplified example of the phone application.

7.4.4 An interactive website

A fourth mode of intervention delivery would be to build an interactive website. This would work by survivors choosing the stage of the treatment they are in, whereupon they would be taken to the pictogram models relating to their stage. They could then choose the experience they wanted to improve, and they would be presented with a list of interventions they could apply (see Figure 7-16). This website again could be used by healthcare providers and survivors alike to improve their communication and as the basis of their consultations.

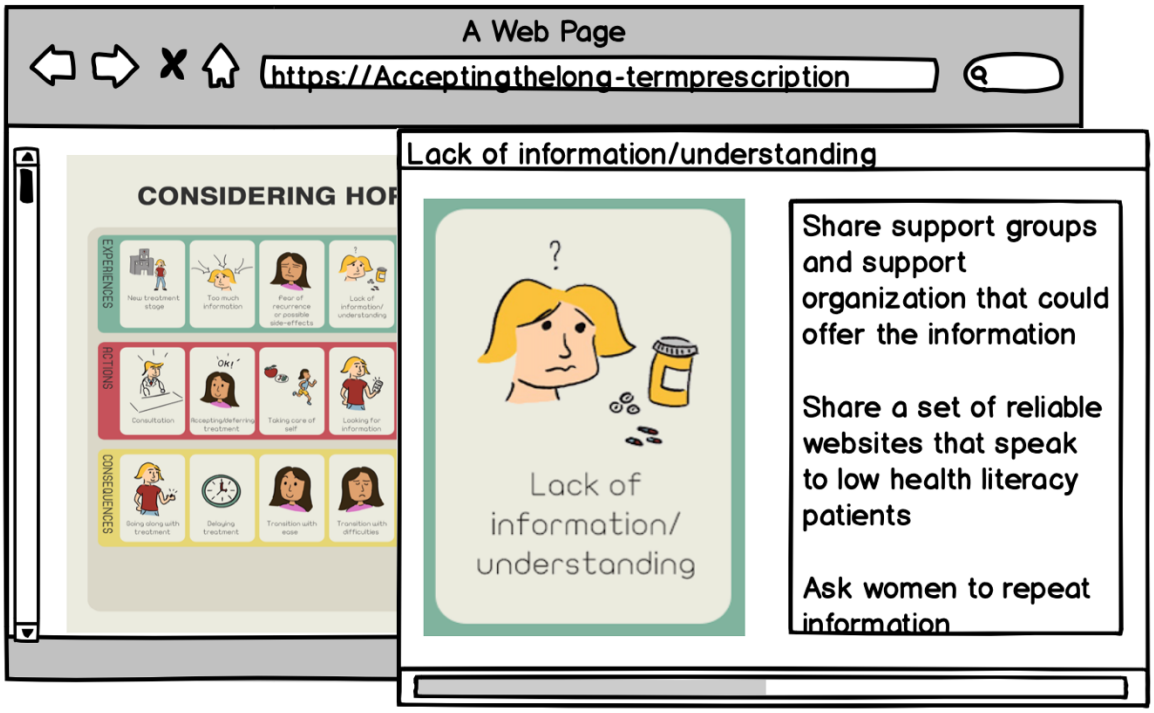


Figure 7-16: A simplified example of an interactive website.

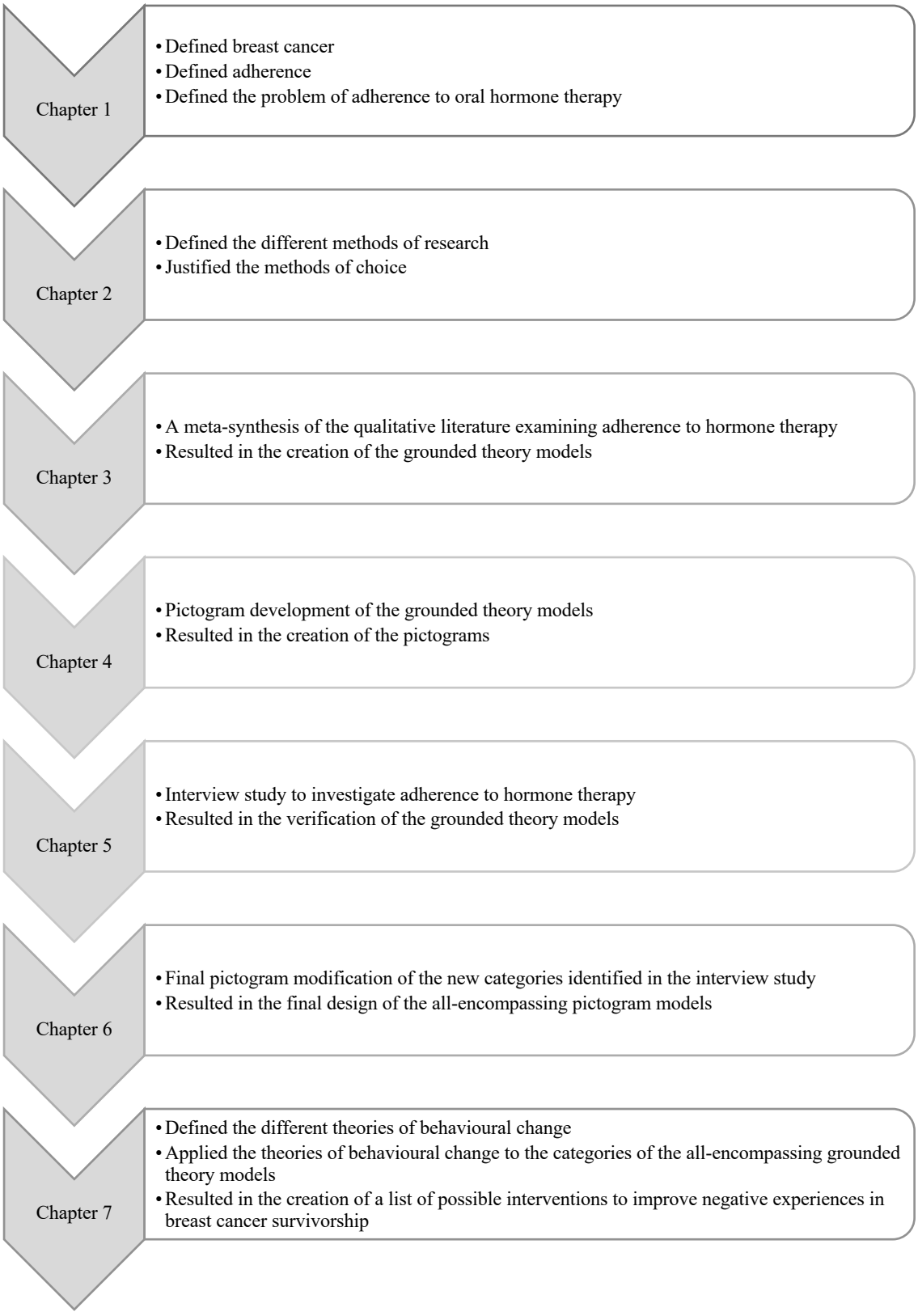
7.5 Conclusion

Developing an intervention is a complicated process. In order to devise something that is not merely theoretical and has the potential to work on a practical level, one must perfectly understand the process one is trying to improve. Previous chapters provided me with detailed insight into what women experience while they are on a hormone therapy treatment. In this final piece of research, I have discussed the various behavioural change theories, while taking a systematic, step-by-step approach to combining the different theories and matching them to intervention functions from the BCW. The list of the possible interventions for each one of the negative experiences is built on the solid foundation of my research. However, the list is not definitive and could be refined and improved over time. Combining these interventions with the pictographic models developed in the previous chapter could also be the foundation of a universal method of communication and consultation.

Chapter 8: Summary and conclusion

In this thesis, it was firstly possible to uncover a world of collectively shared experiences and understandings on breast cancer survivorship by examining commonalities in existing published literature. Then the findings were examined in an interview study with breast cancer survivors and were developed further. The study resulted in the validation and further development of the three grounded theory models: “Guided by the doctors: accepting the long-term prescription”; “Balancing priorities: adhering to the long-term treatment”; and “Taking a chance: stopping the treatment early”. The core category explained the difficulties women face with the initial decision to accept long-term hormone therapy and then the everyday challenge of continuing with the treatment or stopping it prematurely. The findings of both studies were combined into three sets of pictogram designs to capture breast cancer survivors’ experiences on hormone therapy. These pictograms are a steppingstone toward developing an educational tool to inform survivors and healthcare providers alike about the range of possible experiences of women on hormone therapy, which could potentially improve women’s experience on the treatment and in turn their adherence.

8.1 Summary, reflection and significance



Non-adherence to adjuvant hormonal therapy, as in the case with many other conditions, appears to be a complex problem. I started this thesis by looking at the different philosophical approaches to research to decide on the most appropriate methodology to answer the question, "How do women's views and experiences affect medication-taking practices in the long-term treatment of breast cancer?". The choice between quantitative and qualitative methods was guided by my ultimate goal to explore the phenomenon thoroughly, make sense of breast cancer survivors' decision-making process, take an all-inclusive approach to answer the research question, connect with my participants and capture their experiences in a systematic manner. I decided, therefore, to adopt qualitative principles in my research. Until now, no theories adequately explained women's non-adherence to hormone therapy. Which is why I wanted to develop a theory that captures what women are going through grounded in the information they provide. To do so, I decided to adopt grounded theory methodology in my research.

My project started with a meta-synthesis of the qualitative literature that examined women's adherence to their hormone therapy prescription. To do so, I decided to adopt grounded theory synthesis as the method of analysis so that my findings could meaningfully feed into the next phase of my investigation. The study resulted in the development of three main categories; 1) 'Guided by the doctors: accepting the long-term prescription'; 2) 'Balancing priorities: adhering to the long-term treatment'; and 3) 'Taking a chance: stopping the treatment early'. The core category I developed to encapsulate the whole process is "Hobson's choice or a horned dilemma?". The categories in this study were developed inductively in line with grounded theory methodology, to avoid biases and being influenced by preconceptions. The core category "Hobson's choice or a horned dilemma?", despite being developed from scratch, happens to fit the Necessity−Concern Framework (Horne and Weinman, 1999). However, my findings go beyond the Necessity−Concern Framework to capture the actual experiences and beliefs of women on hormone therapy and explore how those experiences and beliefs influence their behaviour.

This was not an easy process and I soon ran into multiple practical issues that I needed to work around. The first was related to the retrieval process. In 2016, when I began my work, there were only seven qualitative studies that had covered similar topics; by 2019 this number had risen to 24. This sudden rise shows the interest of healthcare

professionals and researchers alike in understanding this phenomenon. In practical terms, however, it complicated the process, continually creating additional work. The second practicality has to do with the lack of clear and precise instructions on how to use grounded theory synthesis to guide data collection. I therefore decided to employ a different method, meta-ethnography, to guide my data collection, thus using it to identify first-order constructs and second-order constructs from the original papers. The third practicality has to do with the fact that the 24 studies used different qualitative methods, presented quotations from different numbers of participants and included different characteristic information about their participants. This difficulty was overcome by creating a heterogenous dataset of quotations that were fitted to the timeline of the treatment, enabling me to move forward with the task at hand. Finally, the most important practicality I had to overcome had to do with the grounded theory methodology itself and how to make sure the deconstruction of the data did not influence its purity. To overcome this and make sure all meanings were preserved, I had to work hand-in-hand with my primary supervisor by organizing multiple meetings to discuss, document, manage and identify patterns and interconnections between the different quotations. This study took longer than I had originally anticipated but resulted in the creation of an all-encompassing theory that formed the basis of my future work. My work also provides detailed guidance to others on how to complete a grounded-theory synthesis of qualitative data within primary studies, and that too I believe to be an original contribution to the field.

The major limitation of the literature review study concerns my lack of access to the original interview transcripts, which meant my analysis had to be completed using only quotations that were extracted by the original authors to include in their papers, and their respective interpretations. Nonetheless, the model was based on 801 quotes, extracted from 24 studies to reflect the experiences of 610 survivors of breast cancer. I believe that this provided a sufficient basis for developing a theoretical understanding of women's beliefs and experiences while on a hormone therapy prescription.

However, after finishing the meta-synthesis study I wanted to embark on my own interview study with breast cancer survivors who had taken or were taking hormone therapy, in order to validate and improve the grounded theory models and examine them against a full dataset of interviews, thereby overcoming the study limitation referred to. Before doing so, however, I needed to find a way to overcome the length and complexity

of the models to my interview participants. This was because I wanted to validate the models with my participants but needed a way to communicate my findings to them. One way to convey knowledge and facilitate understanding, in the health field as in any other, is by using pictograms. So, I took the decision to develop the three models into three sets of pictograms to make them easier to understand, whatever the user's health literacy level. In developing the pictograms, I used simple, easy-to- understand pictures and language, took account of the sensitivity of the phenomenon and included healthcare professionals in the design creation. I also involved a professional graphic designer to help in producing the pictograms.

After designing the pictograms, I was ready to embark on my own interview study. Before starting I needed to obtain ethics approval from the University of Reading Research Ethics Committee. I had to consider factors such as privacy, autonomy, confidentiality, possible participants' distress related to the nature of the discussed condition, female participants having to discuss their condition with a male researcher, normalization of unhelpful behaviours, creating self-doubt and, finally, "labelling" individuals (e.g. as non-adherent). To meet the requirements of the committee I also needed to prepare in advance an interview guide, recruitment poster, information sheet and consent form.

As interviews progressed, I continually modified my interview guide to examine new areas of interest arising from the interviews, in accordance with the theoretical sampling technique of grounded theory. The data collection and data analysis went hand in hand in a simultaneous manner. The data analysis process followed the same trajectory as the meta-synthesis study I had already undertaken, moving between open, axial and selective coding, from one level of abstraction to another, back and forth between the various coding levels in a non-linear manner. There were some practical difficulties that I had to work around to ensure that my data was fully examined. These were related to my ability to distinguish the line between codes and categories, given the fact that the categories had been defined previously. Therefore, the open coding process in this study was a combination of inductive and deductive thinking. The challenge here was trying not to force the data into the set of concepts that had already been developed, allowing it instead to create new concepts if possible and tell the story the participants were trying to portray. The axial coding process was somewhat different this time. The codes I used in the open

coding process fit the category in the paradigm perfectly, so open and axial coding not only took place simultaneously but also shared a lot of similarities. New categories were developed further and were used to drive the theoretical sampling process, thus changing the direction of recruitment and future interviews. Due to the fact that this work was a continuation from the meta-synthesis study, data saturation was soon reached. After conducting 14 interviews I reached code saturation, which is in line with the findings of Hennink et al. (2017). Selective coding and the ability of the core category "Hobson's choice or a horned dilemma?" to encapsulate all new information was also examined.

The study resulted in the validation and further development of the three grounded theory models: "Guided by the doctors: accepting the long-term prescription"; "Balancing priorities: adhering to the long-term treatment"; and "Taking a chance: stopping the treatment early". With the help of my supervisor, the external designer who designed the original pictograms, and the ten panel members who validated them, the new categories were drawn, validated and added to the pictograms models, producing a final set of drawings. The core category of my study "Hobson's choice or a horned dilemma?" theorizes that women on a hormonal treatment for the management of breast cancer can be considered broadly a behaving according to three idea. The first is where women think of the treatment as a Hobson's choice; here, women are more likely to adhere to the treatment due to their beliefs about its necessity and are more tolerant of the side-effects of the treatment. The second is where women on a hormonal treatment think of it as a horned dilemma; here, women if faced with a difficulty are more inclined to stop the treatment, they are less tolerant to side-effects and their beliefs about the treatment necessity are not as strong as the first type of women. The third is where women on a hormonal medication start the treatment thinking of it as a Hobson's choice, but when adherence becomes difficult, start to change their view, the decision about whether or not to continue the treatment becoming a horned dilemma. The change in their perception does not happen overnight. It is an active process, unfolding as the woman passes through multiple experiences (either positive or negative) over the period of the treatment. These negatives occupy an area in which healthcare providers need to intervene, for if these experiences are not somehow improved they have the capacity to drive survivors to change their perception, turning what was once a Hobson's choice into a horned dilemma.

The major difference between conducting a meta-synthesis study dealing only with quotations, and a full interview study dealing with a complete dataset of interviews, is that the meta-synthesis study failed in capturing the dynamic sense of participants' experiences. Quotations were dealt with as facts because they lacked a sense of progression: in a way, they felt one-dimensional. The difference in the interview study was that I was dealing with full interviews where I was able to capture the dynamic progression of the treatment and the participant experiences. Thus, the interview study provided a more vivid understanding of what women go through during the treatment.

The findings of my studies suggest a patient-centred approach that takes into account survivors' circumstances and beliefs if adherence is to be improved. My study illustrates the importance of knowledge to women at the different stages of the treatment. It suggests that empowering women with knowledge about the treatment and setting appropriate expectations beforehand, especially about the side-effects, could help improve their experience of taking hormone therapy. The importance of knowledge is highlighted across the different parts of my PhD thesis. It is a very important factor that contributes greatly to breast cancer survivors' experiences and their decision-making process. Being knowledgeable about the treatment, its side-effects, how it works, when to take it and for how long, all such information is essential for the success of the therapy. In some cases, even if women lack the knowledge themselves, having a friend or a family member who is knowledgeable can be helpful to them. My findings suggest that participants who were knowledgeable about the treatment or had someone close who was well-informed, had a better overall experience. However, knowledge was not only survivor- related; healthcare providers' lack of knowledge was also evident from the interviews. Breast cancer survivors meet with their cancer specialist once a year. In between these visits, GPs are the ones responsible for providing the women with care. The data from this study show a lack of trust and belief in GPs' knowledge and their ability and to provide the necessary help and support.

The pictogram models are the proposed educational tool for use throughout the treatment, making it possible to probe for and explore a range of issues that might not otherwise be addressed and also to inform survivors and healthcare providers alike about the experiences of women on hormone therapy. In this thesis, I highlight the importance of knowledge during every phase of the treatment. By both women and healthcare providers

being better informed throughout, we could potentially reduce complications and misunderstandings, improving women's experience on the treatment and in turn their adherence. The pictograms could also be used during consultations to help communication between breast cancer survivors and their healthcare providers. Moreover, they could be employed by healthcare providers as memory triggers to help survivors remember their experience and thus help them share any negative aspect of it they may have forgotten.

After developing an all-encompassing theory, and the pictogram models, using the COM-B model and the BCW I was able to develop a list of interventions that could be used to improve survivors' overall experience. The suggested interventions could be delivered with the help of the pictogram models in the form of interactive posters (with/without NFC) tags, a deck of interactive cards (with/without NFC tags), a phone application or an interactive website. The interventions are not definitive and would need verifying in clinical settings. However, it is a step in what could prove useful in the future for breast cancer consultations.

My study and the pictogram models have the potential to benefit not only breast cancer survivors, but also moderate to high risk women who are prescribed hormonal therapy as prophylaxis against breast cancer. As shown in this thesis, hormone therapy is not an easy medication to take. And even survivors have difficulties continuing on the treatment, despite having experienced the condition already. In 2019, NICE updated guidelines for breast cancer prevention to suggest the following (NICE, 2019):

> 1) Offer tamoxifen for five years to premenopausal women at high risk of breast cancer unless they have a past history or may be at increased risk of thromboembolic disease or endometrial cancer.
> 2) Offer anastrozole for five years to postmenopausal women at high risk of breast cancer unless they have severe osteoporosis.
> 3) Consider tamoxifen for five years for premenopausal women at moderate risk of breast cancer, unless they have a past history or may be at increased risk of thromboembolic disease or endometrial cancer.
> 4) Consider anastrozole for five years for postmenopausal women at moderate risk of breast cancer unless they have severe osteoporosis.

Tamoxifen and aromatase inhibitors are now offered to women at moderate to high risk of developing breast cancer as prophylaxis. The importance of knowledge is highlighted multiple times across this thesis. Women need to be educated in advance to be able to make an informed decision. This is more the case with women who have not experienced cancer before. Expecting healthy women to adhere to these difficult medications without providing them with suitable information in advance is arguably unrealistic. My research and the pictogram models I developed in this thesis could provide these women with the knowledge they need in a simple and easy to understand manner, no matter their health literacy level.

8.2 Validation of the study quality

The issues of validity and trustworthiness are very important in any research study, whether quantitative or qualitative. However, the term quality is still vague in qualitative research, due to the fact that qualitative research is both scientific and artistic in nature. However, creativity is not enough to ensure scientific results. I find myself agreeing with Whittemore et al. (2001) in the belief that it is essential to preserve the innovative and elegant properties of qualitative research while at the same time balancing them with reasonable claims built on a plethora of evidence with a clear description of the used methodology. I will assess the quality of my research using the criteria established by Lincoln and Guba (1985). These criteria are: credibility, dependability, confirmability, transferability and reflexivity.

8.2.1 Credibility

Credibility in qualitative research is about confidence in the findings' representation of the participant experiences. The strategies recommended by Lincoln and Guba (1985) to evaluate a study's validity are prolonged engagement, persistent observation, triangulation, peer debriefing, member checking and a well-established adoption of the chosen research method.

8.2.1.1 Prolonged engagement and persistent observation

I have been involved with the data of this study since I started the second year of my PhD program in the year 2017. This prolonged engagement made me aware of all the variety in the data, which in turn helped me explore women's experiences in detail, to develop categories and build relationships. Not only the length of my engagement but also the fact that I began my PhD with a meta-synthesis study of the published qualitative literature, meant that I was able to explore the different perspectives of various researchers and observe their representation of the issues that were most relevant to the subject matter from different points of view.

8.2.1.2 Triangulation

Triangulation is about using multiple methods, data sources and analysts in an investigation in order to develop an understanding of a phenomenon (Lincoln and Guba, 1985). I started my research by conducting a meta-synthesis study, which resulted in the development of an all-encompassing grounded theory model based on 801 quotes, extracted from 24 studies to reflect the experiences of 610 survivors of breast cancer. I believe that this provided a sufficient basis for developing a theoretical understanding within the context of a qualitative meta-synthesis. Subsequently, I conducted my own interview study, for which I interviewed 14 participants in two different settings. This allowed me to examine, validate and further explore the experience of women on a hormonal treatment. The analysis process was carried out with the help and under the supervision of my supervisor, Professor Parastou Donyai. Triangulation was thus automatically achieved, in the form of method triangulation (two different methods), sources triangulation (published qualitative studies and my own interviews) and lastly, analyst triangulation (carried out by myself and my supervisor).

8.2.1.3 Peer debriefing

Peer debriefing is about examining your own biases, assumptions, logic and methods by presenting your finding to others who are experienced in the field (Lincoln and Guba, 1985). Along with me, my supervisor was involved in planning the studies, data collection, data analysis (coding and interpretation) and theory development. As part of

my PhD I met on a weekly basis with my supervisor, Professor Parastou Donyai, to discuss findings and review theoretical ideas. Also, throughout my PhD I regularly presented my finding to colleagues in scheduled PhD group meetings in order to get their feedback and confirm to myself that my emergent theory would appear sensible and plausible to the unbiased outsider.

8.2.1.4 Member checking

Member checking is regarded by Lincoln and Guba (1985) as the most important technique for establishing credibility. The technique is about checking the analytical categories, interpretations and research conclusion with the participant group that the data is purportedly representing. By design, as part of my interviews, I shared the grounded theory models I developed from the meta-synthesis study with breast cancer survivors. In Chapter 4, I presented their responses to these models, with all of them finding their own story in the emergent theory. Also, after finishing the analysis of my interview study, I prepared a detailed report of my main findings and sent it to all my interviewees to satisfy them that they were accurately represented.

8.2.1.5 Methodological consistency

In my research I adopted the Corbin and Strauss (2014) method of grounded theory, applying their detailed description of the methodology. In Chapters 3 and 5 I have described my methodology in some detail. Data collection, data analysis and theory development were described step-by-step to make sure anyone reading this thesis would understand exactly what I did, when I did it, and how adherent I was to Straussian method of grounded theory. In addition, I was supervised by Professor Parastou Donyai, who has considerable grounded theory experience and expertise (Almutairi et al., 2018; Ibrahim et al., 2016).

8.2.2 Dependability and confirmability

Dependability is demonstrated by the ability to track down findings and interpretations to the pure data from which they were developed (Lincoln and Guba, 1985), while confirmability is attained by the ability to establish that interpretations are derived from

the data and that they are not influenced by the researcher's biases (Lincoln and Guba, 1985). Lincoln and Guba (1985) theorize that dependability and confirmability are closely related and cannot be found one without the other. The technique to establish dependability and confirmability is called "audit". In Chapters 3 and 5 of this research I provided details of the data and my interpretation of the concepts and categories, thus providing an audit trail allowing readers to confirm that findings are logical and traceable to the original set of data.

8.2.3 Transferability

Transferability is defined by Lincoln and Guba (1985) as the "the potential usefulness of the results and theory in explaining the underlying process identified in the substantive theory for a similar group of individuals". Transferability is tricky to establish, however. The technique used to ascertain it is termed "thick description" (Lincoln and Guba, 1985). In Chapters 3 and 5, I set out in detail the method of data collection, recruitment, participant characteristics, and setting, in order to convey the phenomenon I studied. Also, I presented the context in which the findings were established, thereby allowing anyone reading this thesis to assess which other situations and contexts the findings could be transferred to.

8.2.4 Reflexivity

Objectivity in qualitative research is not attainable, no matter how unbiased one tries to be; who we are as people must always influence our research findings (Corbin et al., 2014; Charmaz, 2014). Therefore, it is always suggested that to understand a given piece of research, one must first try to understand who the researcher is, beyond their name and professional affiliations (Dodgson, 2019). It is a *sine qua non*, in short, to understand a researcher's positionality on the matter being investigated. This level of transparency and clarity is required for any qualitative work to ensure its quality (Gentles et al., 2014; Dodgson, 2019). This is known as "reflexivity". Grounded theory is no exception to other qualitative methods in urging reflexivity. Both Corbin et al. (2014) and Chamaz (2014) discuss the importance of reflexivity in their books, though they did not provide any information on how to incorporate it into research. A study by Gentles et al. (2014),

however, does provide a methodologically consistent approach to reflexivity in grounded theory to help researchers present the elements of reflexivity in their work.

To ensure the reflexivity of the present study, it follows that I must outline where I am coming from as a researcher (Corbin et al., 2014; Gentles et al., 2014). Who I am and what I have done, after all, play an important role in influencing my research and findings. I graduated from Riyadh Colleges of Dentistry and Pharmacy in 2012. I then worked as a pharmacist in Prince Salman Bin Abdulaziz Hospital in Riyadh for four months. In January 2013, I moved into academia as a teaching assistant at the Clinical Pharmacy Department, College of Pharmacy, in Shaqra University, Saudi Arabia, while at the same time working as a part-time pharmacist at Al Dawadmi General Hospital. In 2016, I was awarded a Master of Science degree in clinical pharmacology by King's College London, later that year starting my PhD at the University of Reading. My work as a pharmacist meant that hormone therapy for the management of breast cancer was not new to me. However, my knowledge did not extend beyond a basic understanding of how the treatment works and why it is prescribed. Before starting my PhD I had no knowledge about women's experiences with hormone therapy. Rather than being a disadvantage, however, the fact that the topic was new to me, made me more open and aware, enabling me to bring a fresh eye to the concepts developed in this research area and to avoid biases and preconceptions that might have influenced my interpretations.

This study is my first attempt at qualitative research. Before starting my PhD I had no knowledge of any qualitative research methods and thus no preference for any particular one. I chose grounded theory because I believed it to be the method best suited to my research, for reasons I provided in Chapter 2. Due to the fact that my knowledge about women's experiences with hormone therapy in breast cancer was limited, I decided to start my research with a meta-synthesis study. My original assumption was that this would be quite similar to doing a standard systematic review. However, as I understood more about the complexities of meta-synthesis, I started to recognize the differences and to grasp how much more knowledge a meta-synthesis could potentially bring to an area of research such as the one I had entered. The results of the meta-synthesis helped me develop the interview guide for my own interviews and gain an understanding of the phenomenon in the form of generating a grounded theory.

One of the defining social differences is gender. As a male researcher, the effect of my gender on female participants' ability to share sensitive and uncomfortable experiences was something I needed to consider carefully before embarking on my interviews. I come from a different cultural background to that of the participants − one where segregation between men and women is the norm. Speaking about upsetting experiences between different genders is not something I was used to. This was one of the ethical issues I identified in advance when I was preparing my ethics application. In consequence, I tried to minimize gender influence on the interviews as much as possible by offering participants the choice to either bring someone along with them to the interview or have my (female) supervisor attend it with me. However, all participants decided to attend the interview alone. Also, despite the nature of the condition and the sensitivity of the topic in question, the interviews themselves were a warm and supportive human interaction, where gender played no significant role. I do not think gender was an issue in my study, and I do not believe it affected my participants' willingness to share sensitive experiences.

During my research, I did not have prior knowledge of my participants. The only information they knew about me personally was that I was a researcher and that the interview study was part of my PhD. Also, I presented myself as a PhD student working in academia; I did not want to influence their responses by presenting myself as a pharmacist, hoping to make sure their answers to the questions were honest and not influenced by what they might think I would want to hear from them if they were aware of me being a healthcare provider.

As a novice researcher, I had little to no prior interviewing experience. Therefore, I decided to construct a research persona from pre-existing aspects of my character. I felt that by doing so I would have more confidence in my interviewing ability and be able to promote comfort and reduce distance between myself and the participants. Due to the sensitive and personal nature of breast cancer, and the emotional aspect of prompting those being treated for the condition to remember bad experiences, I tried to the best of my ability to create a safe, empathic and sharing environment for my participants. Fostering a persona that reduced distance resulted in a warm and trusting interviewing environment, to the extent that many of the participants indicated that they enjoyed the interview experience.

My interest in adherence research is not itself new. My MSc dissertation was titled *Medication Non-Adherence: "It's not the patient's fault".* However, it was a general review of adherence research, without a specific focus on a certain condition. I was drawn to the present project because I believe in the importance of adherence research and the need to understand patients' perspectives on the matter. This project was offered to me by my supervisor, Professor Parastou Donyai, and I accepted it directly for intellectual reasons. I had no specific interest in breast cancer before starting my PhD but my interest in adherence provided a compelling reason for my acceptance. I believe that my lack of previous experience with breast cancer, indeed my lack of any existing views on the matter whatsoever, together with my lack of experience also of qualitative research methods, actually had a positive impact on my research by eliminating any biases that might otherwise have arisen.

8.3 Future work

Despite the all-inclusive approach of conducting the meta-synthesis and then the interview study, the lack of qualitative studies similar to this one in the region of the Middle East is evident. To my knowledge, there has to this day been no study examining the experiences of women breast cancer survivors in Saudi Arabia. This is despite breast cancer being the most newly diagnosed cancer in the kingdom among women (Alotaibi et al., 2018). The effect of cultural differences on women experiences while on hormone therapy is an area of research that interests me greatly. Notably, the meta-synthesis data was not enough to come-up with accurate interpretations about the effect of different cultures on the whole process. Therefore, my next step will be to take the models and pictograms I created to conduct an interview study in Saudi Arabia, to try and capture the differences in experiences and to examine the effect of culture and religion on women experiences in comparison with women from the UK.

When the complete universality of these models is obtained, the next step is to assess the benefits of using the pictogram models I developed in clinical practice. Future research should evaluate the practical utility of the pictograms within a clinical setting either in the UK or elsewhere to assess the benefits of using them as a communication tool to

inform breast cancer survivors during their prescription and follow-up visits, in addition to their everyday lives. In order to do so, I started designing a booklet that women survivors could use during their consultation visits. The aim of these booklets is to help survivors communicate their bad experiences and worries with their health care provider. Also, the booklet work as a memory trigger to help survivors record and recall the experience they want to share with their health care provider before going to the meeting.

The suggested interventions are promising. However, further research should assess the applicability and effectiveness of using the pictograms and the suggested interventions in a clinical setting, to assess how they influence breast cancer survivors' adherence and their medication-related behaviours generally. In a simplified manner, this could be done by conducting a quantitative study to compare the effectiveness of these models by comparing between two groups of breast cancer survivors who were prescribed hormone therapy for the management of their condition. One group would be introduced to the pictograms (intervention group) and the other would be a control group with no knowledge of the pictograms' existence. The adherence rate of the two groups and the potential effect on the overall survival rate would then be measured to see if there is any differences between them.

The list of interventions presented in Chapter 7 was developed on the basis of solid research to match the intervention functions of the BCW. However, the intervention list is based solely on my point of view. Interviewing healthcare providers, GPs, specialists, breast cancer nurses and pharmacists about the applicability of these intervention in clinical settings, and trying to identify other, perhaps more applicable ones, could provide us with a more comprehensive list. For example, an interview study could be undertaken that recruits health care providers to obtain their input. This could be the best way to develop the list of interventions into something more realistic and relatable to clinical sittings.

Lastly, after creating the universally inclusive models and a more comprehensive list of intervention with the input of health care providers that are more relatable to clinical settings, I need to look at the mode of delivery of these interventions. As mentioned in the previous chapter, creating an interactive website or an interactive phone application could be the best way to apply the intervention. It would be accessible by survivors and

health care providers anywhere and everywhere. This could be obtained with the help of a computer programmer. Afterward, the utility and effectiveness of these models could be assessed in a larger more comprehensive way using a larger population. This step could make the models created in this thesis the first step toward the development of a standard consultation tool in the UK, Saudi Arabia or anywhere in the world that have the potential to improve adherence and concordance in this patient group.

References:

Adams, N. et al. (2017) Evaluating survivorship experiences and needs among rural African American breast cancer survivors. *Journal of Cancer Education*. [Online] 32 (2), 264–271.

Ahlstedt Karlsson, S. et al. (2019) 'It is not just any pill': women's experiences of endocrine therapy after breast cancer surgery. *European Journal of Cancer Care*. [Online] 28 (3), e13009.

Almutairi, S. et al. (2018) The health professional experience of using antipsychotic medication for dementia in care homes: a study using grounded theory and focussing on inappropriate prescribing. *Journal of Psychiatric and Mental Health Nursing*. [Online] 25 (5–6), 307–318.

Alotaibi, R. M. et al. (2018) Breast cancer mortality in Saudi Arabia: Modelling observed and unobserved factors. *PLoS one*. [Online] 13 (10), 1–16.

American Cancer Society (2016) *Breast cancer* [online]. Available from: http://www.cancer.org/cancer/breastcancer/detailedguide/index (Accessed 8 January 2017).

Atkins, L. and Fallowfield, L. (2006) Intentional and non-intentional non-adherence to medication amongst breast cancer patients. *European Journal of Cancer*. [Online] 42 (14), 2271–2276.

Atkins, S. et al. (2008) Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Medical Research Methodology*. [Online] 8 (1), 21.

Ayto, J. A. (2010) 'Horn', in John Ayto (ed.) *Oxford dictionary of english idioms*. Oxford University Press. [online]. Available from: http://www.oxfordreference.com/view/10.1093/acref/9780199543793.001.0001/acref-9780199543793-e-1249 (Accessed 27 February 2019).

Baguley, D. et al. (2012) Prescribing for children: taste and palatability affect adherence to antibiotics: a review. *Archives of Disease in Childhood*. [Online] 97 (3), 293–297.

Barillet, M. et al. (2015) Oral antineoplastic agents: how do we care about adherence? *British Journal of Clinical Pharmacology*. [Online] 80 (6), 1289–1302.

Barnett-Page, E. and Thomas, J. (2009) Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*. [Online] 959.

Barros, I. M. C. et al. (2014) The use of pictograms in the health care: a literature review. *Research in Social and Administrative Pharmacy (RSAP)*. [Online] 10 (5), 704–719.

Bassan, F. et al. (2014) Adherence to oral antineoplastic agents by cancer patients: definition and literature review. *European Journal of Cancer Care*. [Online] 23 (1), 22–35.

Bearman, M. and Dawson, P. (2013) Qualitative synthesis and systematic review in health professions education. *Medical Education*. [Online] 47 (3), 252–260.

Bellanger, M. et al. (2018) Are global breast cancer incidence and mortality patterns related to country-specific economic development and prevention strategies? *Journal of Global Oncology*. [Online] (4), 1–16.

van Beusekom, M. M. et al. (2018) The extent and effects of patient involvement in pictogram design for written drug information: a short systematic review. *Drug Discovery Today*. [Online] 23 (6), 1312–1318.

Blackwell, B. (1992) Compliance. *Psychotherapy and Psychosomatics*. 58 (3–4), 161–169.

Blalock, S. J. & Reyna, V. F. (2016) Using Fuzzy-Trace Theory to Understand and Improve Health Judgments, Decisions, and Behaviors: A Literature Review. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. [Online] 35 (8), 781–792.

Blows, F. M. et al. (2010) Subtyping of breast cancer by immunohistochemistry to investigate a relationship between subtype and short and long term survival: a collaborative analysis of data for 10,159 cases from 12 studies. *PLoS Medicine*. [Online] 7 (5). [Online] Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2876119/ (Accessed 18 June 2017).

Bluethmann, S. M. et al. (2017) Deconstructing decisions to initiate, maintain, or discontinue adjuvant endocrine therapy in breast cancer survivors: a mixed-methods study. *Oncology Nursing Forum*. [Online] 44 (3), 101–110.

Bosworth, H. B. (2012) 'Methods for determining medication adherence', in *Enhancing Medication Adherence*. Springer Healthcare Ltd. pp. 17–25. [online]. Available from: http://link.springer.com/chapter/10.1007/978-1-908517-66-1_3 (Accessed 10 September 2015).

Bourmaud, A. et al. (2016) Improving adherence to adjuvant endocrine therapy in breast cancer through a therapeutic educational approach: a feasibility study. *Oncology Nursing Forum; Pittsburgh*. [Online] 43 (3), 94–103.

Brauer, E. R. et al. (2016) 'Winging it': how older breast cancer survivors persist with aromatase inhibitor treatment. *Journal of Oncology Practice*. [Online] 12 (12), 991–1000.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. [Online] 3 (2), 77–101.

Breast Cancer Care (2016) *Chemotherapy* [online]. Available from: https://www.breastcancercare.org.uk/information-support/facing-breast-cancer/going-through-treatment-breast-cancer/chemotherapy (Accessed 18 June 2017).

Brett, J. et al. (2018) Adjuvant endocrine therapy after breast cancer: a qualitative study of factors associated with adherence. *Patient Preference and Adherence*. [Online] 12291–300.

Brown, M. T. and Bussell, J. K. (2011) Medication adherence: WHO cares? *Mayo Clinic Proceedings*. [Online] 86 (4), 304–314.

Cahir, C. et al. (2015) Women's experiences of hormonal therapy for breast cancer: exploring influences on medication-taking behaviour. *Supportive Care in Cancer*. [Online] 23 (11), 3115–3130.

Cameron, L. D. (2010) Temporal Self-Regulation Theory: towards a more comprehensive understanding of health behaviour. *Health Psychology Review*. [Online] 4 (2), 70–74.

Cancer research UK (2019) *What is breast cancer? | Cancer Research UK* [online]. Available from: https://www.cancerresearchuk.org/about-cancer/breast-cancer/about (Accessed 2 March 2020).

Cane, J. et al. (2012) Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implementation Science*. [Online] 7 (1), 37.

Chai, P. R. et al. (2015) Utilizing an ingestible biosensor to assess real-time medication adherence. *Journal of Medical Toxicology*. [Online] 1–6.

Charmaz, K. (2014) *Constructing grounded theory*. SAGE.

Cheng, H. et al. (2017) A qualitative insight into self-management experience among Chinese breast cancer survivors. *Psycho-Oncology*. [Online] 26 (7), 1044–1049.

Clawson, T. H. et al. (2012) Using pictograms for communication. *Military Medicine*. [Online] 177 (3), 291–295.

Cooper, C. et al. (2005) The AdHOC Study of older adults' adherence to medication in 11 countries. *The American Journal of Geriatric Psychiatry*. [Online] 13 (12), 1067–1076.

Corbin, J. et al. (2014) *Basics of qualitative research*. SAGE.

Davies, C. et al. (2013) Long-term effects of continuing adjuvant tamoxifen to 10 years versus stopping at 5 years after diagnosis of oestrogen receptor-positive breast cancer: ATLAS, a randomised trial. *The Lancet*. [Online] 381 (9869), 805–816.

Davis, L. L. (1992) Instrument review: getting the most from a panel of experts. *Applied Nursing Research*. [Online] 5 (4), 194–197.

Demissie, S. et al. (2001) Adjuvant tamoxifen: predictors of use, side-effects, and discontinuation in older women. *Journal of Clinical Oncology*. 19 (2), 322–328.

Dimatteo, M. R. (2004) Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychology*. 23 (2), 207–218.

Dixon, W. M. et al. (1957) Outpatient P.A.S. therapy. *The Lancet*. 273 (7001), 871–872.

Dixon-Woods, M. et al. (2006) Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*. [Online] 6 (1), 35.

Dodgson, J. E. (2019) Reflexivity in qualitative research. *Journal of Human Lactation*. [Online] 35 (2), 220–222.

Donyai, P. (2019) Keep on taking the medicine? *The Psychologist*. 32, 20–25.

Donyai, P. (2012) *Social and cognitive pharmacy: theory and case studies*. Pharmaceutical Press.

Dowse, R. et al. (2011) An illustrated leaflet containing antiretroviral information targeted for low-literate readers: development and evaluation. *Patient Education and Counseling*. [Online] 85 (3), 508–515.

Dowse, R. and Ehlers, M. S. (1998) Pictograms in pharmacy. *International Journal of Pharmacy Practice*. [Online] 6 (2), 109–118.

Dunbar-Jacob, J. et al. (1991) Compliance with antihypertensive regimen. *Annals of Behavioral Medicine*. 13 (1). [online]. Available from: https://stephenson.pure.elsevier.com/en/publications/compliance-with-antihypertensive-regimen(c7c766a8-4853-4243-a6f1-d771ceacc23b).html (Accessed 15 July 2016).

Eaves, Y. D. (2001) A synthesis technique for grounded theory data analysis. *Journal of Advanced Nursing*. [Online] 35 (5), 654–663.

Early Breast Cancer Trialists' Collaborative Group (2015) Aromatase inhibitors versus tamoxifen in early breast cancer: patient-level meta-analysis of the randomised trials. *The Lancet*. [Online] 386 (10001), 1341–1352.

Fabian, C. J. and Kimler, B. F. (2005) Selective estrogen-receptor modulators for primary prevention of breast cancer. *Journal of Clinical Oncology*. [Online] 23 (8), 1644–1655.

Farias, A. J. et al. (2017) Exploring the role of physician communication about adjuvant endocrine therapy among breast cancer patients on active treatment: a qualitative analysis. *Supportive Care in Cancer*. [Online] 25 (1), 75–83.

Findlay, M. et al. (2008) Effective oral chemotherapy for breast cancer: pillars of strength. *Annals of Oncology*. [Online] 19 (2), 212–222.

Fink, A. K. et al. (2004) Patient beliefs and tamoxifen discontinuance in older women with estrogen receptor-positive breast cancer. *Journal of Clinical Oncology*. [Online] 22 (16), 3309–3315.

Flanagan, J. et al. (2016) The experience of initiating oral adjuvant treatment for estrogen receptor-positive breast cancer. *Oncology Nursing Forum*. [Online] 43 (4), 143–152.

Freeman, M. S. (2002) 'Hobson's choice', in *A new dictionary of eponyms*. Oxford University Press. p. [online]. Available from: http://www.oxfordreference.com/view/10.1093/acref/9780195093544.001.0001/acref-9780195093544-e-176 (Accessed 27 February 2019).

Gadkari, A. S. and McHorney, C. A. (2012) Unintentional non-adherence to chronic prescription medications: how unintentional is it really? *BMC Health Services Research*. [Online] 12 (1), 98.

Gentles, S. et al. (2014) A critical approach to reflexivity in grounded theory. *The Qualitative Report*. 19 (44), 1–14.

Girish, C. et al. (2014) A Review on breast cancer. *International Journal of Pharmacy and Biological Sciences*, *4* (2), 47–54.

Given, B. A. et al. (2011) The challenges of oral agents as antineoplastic treatments. *Seminars in Oncology Nursing*. [Online] 27 (2), 93–103.

Glanz, K. et al. (2015) *Health behavior: theory, research, and practice*. John Wiley and Sons.

Glaser, B. G. et al. (1967) The discovery of grounded theory; strategies for qualitative research. *Nursing Research*. 17 (4), 364.

Goss, P. E. et al. (2005) Randomized trial of letrozole following tamoxifen as extended adjuvant therapy in receptor-positive breast cancer: updated findings from NCIC CTG MA.17. *JNCI: Journal of the National Cancer Institute*. [Online] 97 (17), 1262–1271.

Greer, J. A. et al. (2016) A systematic review of adherence to oral antineoplastic therapies. *The Oncologist*. [Online] 21 (3), 354–376.

Guba, E. G. and Lincoln, Y. S. (1994) 'Competing paradigms in qualitative research', in *Handbook of qualitative research*. Thousand Oaks, CA, US: Sage Publications, Inc. 105–117.

Güth, U. et al. (2008) Target and reality of adjuvant endocrine therapy in postmenopausal patients with invasive breast cancer. *British Journal of Cancer*. [Online] 99 (3), 428–433.

Hall, P. and Fong, G. (2007) Temporal self-regulation theory: a model for individual health behavior. *Health Psychology Review*. [Online] 16–52.

Harrow, A. et al. (2014) A hard pill to swallow: a qualitative study of women's experiences of adjuvant endocrine therapy for breast cancer. *Bmj Open*. [Online] 4 (6), 1–10.

Haviland, J. S. et al. (2013) The UK standardisation of breast radiotherapy (START) trials of radiotherapy hypofractionation for treatment of early breast cancer: 10-year follow-up results of two randomised controlled trials. *The Lancet Oncology*. [Online] 14 (11), 1086–1094.

Hawker, S. et al. (2002) Appraising the evidence: reviewing disparate data systematically. *Qualitative Health Research*. [Online] 12 (9), 1284–1299.

Haynes, R. B. and Sackett, D. L. (1979) *Compliance in health care*. Johns Hopkins University Press.

Helgeson, V. S. et al. (2000) Group support interventions for women with breast cancer: who benefits from what? *Health Psychology*. [Online] 19 (2), 107–114.

Hennink, M. M. et al. (2017) Code saturation versus meaning saturation: how many interviews are enough? *Qualitative Health Research*. [Online] 27 (4), 591–608.

Hernández-Ronquillo, L. et al. (2003) Factors associated with therapy noncompliance in type-2 diabetes patients. *Salud Pública De México*. 45 (3), 191–197.

Hershman, D. L. et al. (2010) Early discontinuation and non-adherence to adjuvant hormonal therapy are associated with increased mortality in women with breast cancer. *Breast Cancer Research and Treatment*. [Online] 126 (2), 529–537.

Holmes, E. A. F. et al. (2014) Predicting adherence to medications using health psychology theories: a systematic review of 20 years of empirical research. *Value in Health*. [Online] 17 (8), 863–876.

Horne, R. and Weinman, J. (1999) Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of Psychosomatic Research*. 47 (6), 555–567.

Houts, P. S. et al. (2006) The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling*. [Online] 61 (2), 173–190.

Humphries, B. et al. (2018) Women's beliefs on early adherence to adjuvant endocrine therapy for breast cancer: a theory-based qualitative study to guide the development of community pharmacist interventions. *Pharmacy*. [Online] 6 (2), 53.

Huston, P. and Rowan, M. (1998) Qualitative studies. Their role in medical research. *Canadian Family Physician*. 442453–2458.

Iacorossi, L. et al. (2016) Adherence to oral administration of endocrine treatment in patients with breast cancer: a qualitative study. *Cancer Nursing*. [Online] *41* (1), 57-63.

Ibrahim, K. et al. (2016) Caught in the eye of the storm: a qualitative study of views and experiences of planned drug holidays from methylphenidate in child and adolescent ADHD treatment. *Child and Adolescent Mental Health*. [Online] 21 (4), 192–200.

Ibrahim, K. et al. (2018) The construction and validation of child, adolescent and parental decision aids for considering methylphenidate drug holidays in ADHD. *Pharmacy*. [Online] 6 (4), 122.

Iihara, N. et al. (2004) Beliefs of chronically ill Japanese patients that lead to intentional non-adherence to medication. *Journal of Clinical Pharmacy and Therapeutics*. [Online] 29 (5), 417–424.

Irvine, A. et al. (2013) 'Am I not answering your questions properly?' Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews. *Qualitative Research*. [Online] 13 (1), 87–106.

Iuga, A. O. and McGuire, M. J. (2014) Adherence and health care costs. *Risk Management and Healthcare Policy*. [Online] 735–44.

Jackson, C. et al. (2014) Applying COM-B to medication adherence: a suggested framework for research and interventions. *The European Health Psychologist*. 16 (1), 7–17.

Jin, J. et al. (2008) Factors affecting therapeutic compliance: a review from the patient's perspective. *Therapeutics and Clinical Risk Management*. 4 (1), 269–286.

Johansen, M.-L. et al. (2010) A doctor close at hand: how GPs view their role in cancer care. *Scandinavian Journal of Primary Health Care*. [Online] 28 (4), 249–255.

Johnson, L. A. (2015) Factors influencing oral adherence: qualitative metasummary and triangulation with quantitative evidence. *Clinical Journal of Oncology Nursing*. [Online] 19 (3 Suppl), 6–30.

Jordan, V. C. (2014) Tamoxifen as the first targeted long term adjuvant therapy for breast cancer. *Endocrine-Related Cancer*. [Online] 21 (3), 235–246.

Kahn, K. L. et al. (2007) Patient centered experiences in breast cancer: predicting long-term adherence to tamoxifen use. *Medical Care*. 45 (5), 431–439.

Kardas, P. et al. (2013) Determinants of patient adherence: a review of systematic reviews. *Frontiers in Pharmacology*. [Online] 4. [online]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3722478/ (Accessed 23 January 2020).

Kearney, M. H. (2001) Enduring love: a grounded formal theory of women's experience of domestic violence. *Research in Nursing and Health*. [Online] 24 (4), 270–282.

King, A. and Broggio, J. (2018) *Cancer registration statistics, England − Office for National Statistics* [online]. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/final2016#breast-prostate-lung-and-colorectal-cancers-continue-to-be-the-most-common (Accessed 16 May 2019).

Kiortsis, D. N. et al. (2000) Factors associated with low compliance with lipid-lowering drugs in hyperlipidemic patients. *Journal of Clinical Pharmacy and Therapeutics*. [Online] 25 (6), 445–451.

Kirk, M. C. and Hudis, C. A. (2008) Insight into barriers against optimal adherence to oral hormonal therapy in women with breast cancer. *Clinical Breast Cancer*. [Online] 8 (2), 155–161.

Krigsman, K. (2007) *Refill adherence to long-term drug treatment with a focus on asthma/COPD medication [Elektronisk resurs]*. Uppsala: Acta Universitatis Upsaliensis. [online]. Available from: http://uu.diva-portal.org/smash/get/diva2:170487/FULLTEXT01.pdf (Accessed 10 September 2015).

Kripalani, S. et al. (2007) Development of an illustrated medication schedule as a low-literacy patient education tool. *Patient Education and Counseling*. [Online] 66 (3), 368–377.

Kyngäs, H. A. (1999) Compliance of adolescents with asthma. *Nursing and Health Sciences*. [Online] 1 (3), 195–202.

Kyngäs, H. and Lahdenperä, T. (1999) Compliance of patients with hypertension and associated factors. *Journal of Advanced Nursing*. [Online] 29 (4), 832–839.

Lally, R. N. et al. (2013) Unsupportive social interactions in the weeks immediately following breast cancer diagnosis. *Journal of Psychosocial Oncology*. [Online] 31 (4), 468–488.

Lambert, L. K. et al. (2018) Understanding adjuvant endocrine therapy persistence in breast cancer survivors. *BMC Cancer*. [Online] 18. [online]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6042363/ (Accessed 23 January 2020).

Lash, T. L. et al. (2006) Adherence to tamoxifen over the five-year course. *Breast Cancer Research and Treatment*. [Online] 99 (2), 215–220.

Lawson, V. L. et al. (2005) Understanding why people with type 1 diabetes do not attend for specialist advice: a qualitative analysis of the views of people with insulin-dependent diabetes who do not attend diabetes clinic. *Journal of Health Psychology*. [Online] 10 (3), 409–423.

Lebovits, A. H. et al. (1990) Patient noncompliance with self-administered chemotherapy. *Cancer*. 65 (1), 17–22.

Lehmann, A. et al. (2013) Assessing medication adherence: options to consider. *International Journal of Clinical Pharmacy*. [Online] 36 (1), 55–69.

Lerner, B. H. et al. (1998) Rethinking nonadherence: historical perspectives on triple-drug therapy for HIV disease. *Annals of Internal Medicine*. [Online] 129 (7), 573–578.

Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic inquiry*. SAGE.

van Londen, G. J. et al. (2014) Perspectives of postmenopausal breast cancer survivors on adjuvant endocrine therapy-related symptoms. *Oncology Nursing Forum*. [Online] 41 (6), 660–668.

Lowry, K. P. et al. (2005) Intentional and unintentional nonadherence to antihypertensive medication. *Annals of Pharmacotherapy*. [Online] 39 (7–8), 1198–1203.

Lynn, M. R. (1986) Determination and quantification of content validity. *Nursing Research*. 35 (6), 382.

Lyons, E. and Coyle, A. (2016) Google-Books-ID: VT6PCwAAQBAJ. *Analysing qualitative data in psychology*. SAGE.

Makubate, B. et al. (2013) Cohort study of adherence to adjuvant endocrine therapy, breast cancer recurrence and mortality. *British Journal of Cancer*. [Online] 108 (7), 1515–1524.

Malvezzi, M. et al. (2019) European cancer mortality predictions for the year 2019 with focus on breast cancer. *Annals of Oncology*. [Online]. Available from: https://academic.oup.com/annonc/advance-article/doi/10.1093/annonc/mdz051/5382368 (Accessed 16 May 2019).

Mastroianni, C. M. et al. (2012) Preferences of patients with advanced colorectal cancer for treatment with oral or intravenous chemotherapy. *The Patient: Patient-Centered Outcomes Research*. [Online] 1 (3), 181–187.

McCowan, C. et al. (2008) Cohort study examining tamoxifen adherence and its relationship to mortality in women with breast cancer. *British Journal of Cancer*. [Online] 99 (11), 1763–1768.

Meiklejohn, J. A. et al. (2016) The role of the GP in follow-up cancer care: a systematic literature review. *Journal of Cancer Survivorship*. [Online] 10 (6), 990–1011.

Michie, S. et al. (2005) Making psychological theory useful for implementing evidence based practice: a consensus approach. *Quality & Safety in Health Care*. [Online] 14 (1), 26–33.

Michie, S. et al. (2011) The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation Science*. [Online] 6 (1), 1–12.

Michie, S. et al. (2014) *The behaviour change wheel book: a guide to designing interventions*. London: Silverback Publishing. [online]. Available from: http://www.behaviourchangewheel.com/ (Accessed 23 January 2020).

Montagne, M. (2013) Pharmaceutical pictograms: a model for development and testing for comprehension and utility. *Research in Social and Administrative Pharmacy*. [Online] 9 (5), 609–620.

Moon, Z. et al. (2017) Understanding tamoxifen adherence in women with breast cancer: a qualitative study. *British Journal of Health Psychology*. [Online] 22 (4), 978–997.

Munday, D. et al. (2002) Out-of-hours palliative care in the UK: perspectives from general practice and specialist services. *Journal of the Royal Society of Medicine*. [Online] 95 (1), 28–30.

Murphy, C. C. et al. (2012) Adherence to adjuvant hormonal therapy among breast cancer survivors in clinical practice: a systematic review. *Breast Cancer Research and Treatment*. [Online] 134 (2), 459–478.

NHS (2016) *Breast cancer (female) − Treatment − NHS Choices* [online]. Available from: http://www.nhs.uk/Conditions/Cancer-of-the-breast-female/Pages/Treatment.aspx (Accessed 18 June 2017).

NICE (2002) *Healthcare services for breast cancer.* London: National Institute for Clinical Excellence. [online]. Available from: https://www.nice.org.uk/guidance/csg1/resources/healthcare-services-for-breast-cancer-pdf-2183833837.

NICE (2007) *Overview | Behaviour change: general approaches | Guidance | NICE* [online]. Available from: https://www.nice.org.uk/Guidance/PH6 (Accessed 20 January 2020).

NICE (2009) *Overview | Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence | Guidance | NICE* [online]. Available from: https://www.nice.org.uk/guidance/cg76 (Accessed 20 January 2020).

NICE (2018) *Recommendations | Early and locally advanced breast cancer: diagnosis and management | Guidance | NICE* [online]. Available from: https://www.nice.org.uk/guidance/ng101/chapter/Recommendations#endocrine-therapy (Accessed 16 May 2019).

NICE (2019) *Recommendations | Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer | Guidance | NICE* [online]. Available from: https://www.nice.org.uk/guidance/cg164/chapter/Recommendations#risk-reduction-and-treatment-strategies (Accessed 5 February 2020).

Novick, G. (2008) Is there a bias against telephone interviews in qualitative research? *Research in Nursing and Health*. [Online] 31 (4), 391–398.

O'Brien, M. K. et al. (1992) Adherence to medication regimens: updating a complex medical issue. *Medical Care Research and Review*. [Online] 49 (4), 435–454.

Ogden, J. (2012) *Health Psychology: A Textbook*. Open University Press.

Osterberg, L. and Blaschke, T. (2005) Adherence to medication. *New England Journal of Medicine*. [Online] 353 (5), 487–497.

Owusu, C. et al. (2008) Predictors of tamoxifen discontinuation among older women with estrogen receptor-positive breast cancer. *Journal of Clinical Oncology*. [Online] 26 (4), 549–555.

Park, K.-A. et al. (2010) Factors that affect medication adherence in elderly patients with diabetes mellitus. *Korean Diabetes Journal*. [Online] 34 (1), 55–65.

Partridge, A. H. et al. (2008) Adherence to initial adjuvant anastrozole therapy among women with early-stage breast cancer. *Journal of Clinical Oncology*. [Online] 26 (4), 556–562.

Partridge, A. H. et al. (2003) Nonadherence to adjuvant tamoxifen therapy in women with primary breast cancer. *Journal of Clinical Oncology*. 21 (4), 602–606.

Pellegrini, I. et al. (2010) Women's perceptions and experience of adjuvant tamoxifen therapy account for their adherence: breast cancer patients' point of view. *Psycho-Oncology*. [Online] 19 (5), 472–479.

Phillips, C. J. et al. (2015) Experiences of using the Theoretical Domains Framework across diverse clinical environments: a qualitative study. *Journal of Multidisciplinary Healthcare*. [Online] 8139–146.

Polit, D. F. and Beck, C. T. (2006) The content validity index: are you sure you know what's being reported? Critique and recommendations. *Research in Nursing and Health*. [Online] 29 (5), 489–497.

Ponnusankar, S. et al. (2004) Assessment of impact of medication counseling on patients' medication knowledge and compliance in an outpatient clinic in South India. *Patient Education and Counseling*. [Online] 54 (1), 55–60.

Potosky, A. L. et al. (2011) Differences between primary care physicians' and oncologists' knowledge, attitudes and practices regarding the care of cancer survivors. *Journal of General Internal Medicine*. [Online] 26 (12), 1403–1410.

Pound, P. et al. (2005) Resisting medicines: a synthesis of qualitative studies of medicine taking. *Social Science and Medicine*. [Online] 61 (1), 133–155.

Ralph, N. et al. (2015) The methodological dynamism of grounded theory. *International Journal of Qualitative Methods*. [Online] 14 (4), 1–6.

Richmond, H. (2002) Learners' Lives: A Narrative Analysis. *The Qualitative Report*. 7 (3), 1–14.

Ridd, M. et al. (2009) The patient–doctor relationship: a synthesis of the qualitative literature on patients' perspectives. *The British Journal of General Practice*. [Online] 59 (561), 116–133.

Rieger, K. L. (2019) Discriminating among grounded theory approaches. *Nursing Inquiry*. [Online] 26 (1), 1–12.

Rohret, L. and Ferguson, K. J. (1990) Effective use of patient education illustrations. *Patient Education and Counseling*. [Online] 15 (1), 73–75.

Rose, P. W. et al. (2001) Referral of patients with a family history of breast/ovarian cancer—GPs' knowledge and expectations. *Family Practice*. [Online] 18 (5), 487–490.

Rust, C. and Davis, C. (2011) Health literacy and medication adherence in underserved African-american breast cancer survivors: a qualitative study. *Social Work in Health Care*. [Online] 50 (9), 739–761.

Sabaté, E. (2003) *Adherence to long-term therapies: evidence for action*. World Health Organization.

Sale, J. E. M. et al. (2002) Revisiting the quantitative-qualitative debate: implications for mixed-methods research. *Quality and Quantity*. [Online] 36 (1), 43–53.

Sedjo, R. L. and Devine, S. (2010) Predictors of non-adherence to aromatase inhibitors among commercially insured women with breast cancer. *Breast Cancer Research and Treatment*. [Online] 125 (1), 191–200.

Senior, V. et al. (2004) Self-reported adherence to cholesterol-lowering medication in patients with familial hypercholesterolaemia: the role of illness perceptions. *Cardiovascular Drugs and Therapy*. [Online] 18 (6), 475–481.

Singletary, S. E. and Connolly, J. L. (2006) Breast cancer staging: working with the sixth edition of the AJCC Cancer Staging Manual. *CA: A Cancer Journal for Clinicians*. 56 (1), 37–47; quiz 50–51.

Slevitch, L. (2011) Qualitative and quantitative methodologies compared: ontological and epistemological perspectives. *Journal of Quality Assurance in Hospitality and Tourism*. [Online] 12 (1), 73–81.

Smith, E. (2012) *Tamoxifen – the start of something big* [online]. Available from: https://scienceblog.cancerresearchuk.org/2012/10/15/high-impact-science-tamoxifen-the-start-of-something-big (Accessed 5 March 2020).

Smith, I. E. and Dowsett, M. (2003) Aromatase inhibitors in breast cancer. *New England Journal of Medicine*. [Online] 348 (24), 2431–2442.

Smith, J. A. & Osborn, M. (2015) Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*. [Online] 9 (1), 41–42.

Smith, L. K. et al. (2005) Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *The Lancet*. [Online] 366 (9488), 825–831.

Sniehotta, F. F. et al. (2014) Time to retire the theory of planned behaviour. *Health Psychology Review*. [Online] 8 (1), 1–7.

Spring, L. M. et al. (2016) Neoadjuvant endocrine therapy for estrogen receptor–positive breast cancer: a systematic review and meta-analysis. *JAMA Oncology*. [Online] 2 (11), 1477–1486.

Starks, H. and Brown Trinidad, S. (2007) Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*. [Online] 17 (10), 1372–1380.

Steiner, J. F. and Prochazka, A. V. (1997) The assessment of refill compliance using pharmacy records: methods, validity, and applications. *Journal of Clinical Epidemiology*. 50 (1), 105–116.

Stern, P. N. and Harris, C. C. (1985) Women's health and the self-care paradox: a model to guide self-care readiness. *Health Care for Women International*. [Online] 6 (1–3), 151–163.

Strauss, A. and Corbin, J. M. (1990) *Basics of qualitative research: grounded theory procedures and techniques*. Thousand Oaks, CA, US: Sage Publications, Inc.

Strauss, A. L. (1987) *Qualitative analysis for social scientists*. [Online]. [online]. Available from: /core/books/qualitative-analysis-for-social-scientists/1EBB3B490B28C39D7A33EB12A58B211B (Accessed 28 January 2020).

Sung, J. C. et al. (1998) Factors affecting patient compliance with antihyperlipidemic medications in an HMO population. *The American Journal of Managed Care*. 4 (10), 1421–1430.

Teller, M. E. (1988) *The tuberculosis movement: a public health campaign in the progressive era*. New York: Greenwood Press.

Thorne, S. et al. (2004) Qualitative metasynthesis: reflections on methodological orientation and ideological agenda. *Qualitative Health Research*. [Online] 14 (10), 1342–1365.

Tong, A. et al. (2012) Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*. [Online] 12181.

Trusson, D. and Pilnick, A. (2017) Between stigma and pink positivity: women's perceptions of social interactions during and after breast cancer treatment. *Sociology of Health and Illness*. [Online] 39 (3), 458–473.

University of Reading (2012) *Ethics guidance* [online]. Available from: https://www.reading.ac.uk/internal/academic-and-governance-services/research-ethics/RECwhatdoIneedtodo.aspx (Accessed 12 September 2019).

Verbrugghe, M. et al. (2017) Factors influencing the process of medication (non-)adherence and

(non-)persistence in breast cancer patients with adjuvant antihormonal therapy: a qualitative study. *European Journal of Cancer Care*. [Online] 26 (2), 1–11.

Vermeire, E. et al. (2001) Patient adherence to treatment: three decades of research. A comprehensive review. *Journal of Clinical Pharmacy and Therapeutics*. [Online] 26 (5), 331–342.

Vrijens, B. et al. (2012) A new taxonomy for describing and defining adherence to medications. *British Journal of Clinical Pharmacology*. [Online] 73 (5), 691–705.

Walsh, D. and Downe, S. (2005) Meta-synthesis method for qualitative research: a literature review. *Journal of Advanced Nursing*. [Online] 50 (2), 204–211.

Waltz, C. F. and Bausell, B. R. (1981) *Nursing research: design statistics and computer analysis*. Philadelphia: F. A. Davis

Wei, C. et al. (2017) The patient-provider discordance in patients' needs assessment: a qualitative study in breast cancer patients receiving oral chemotherapy. *Journal of Clinical Nursing*. [Online] 26 (1–2), 125–132.

Wells, K. J. et al. (2016) Barriers and facilitators to endocrine therapy adherence among underserved hormone-receptor-positive breast cancer survivors: a qualitative study. *Supportive Care in Cancer; Heidelberg*. [Online] 24 (10), 4123–4130.

Whittemore, R. et al. (2001) Validity in qualitative research. *Qualitative Health Research*. [Online] 11 (4), 522–537.

WHO (2018a) *Cancer today* [online]. Available from: http://gco.iarc.fr/today/data/factsheets/cancers/20-Breast-fact-sheet.pdf (Accessed 16 May 2019).

WHO (2018b) *WHO | Breast cancer: prevention and control* [online]. Available from: http://www.who.int/cancer/detection/breastcancer/en/ (Accessed 16 May 2019).

Wickersham, K. et al. (2012) 'Keeping the boogie man away': medication self-management among women receiving anastrozole therapy. *Nursing Research and Practice*. [Online] 1–9.

Wild, M. R. et al. (2004) Can psychological factors help us to determine adherence to CPAP? A prospective study. *European Respiratory Journal*. [Online] 24 (3), 461–465.

Wouters, H. et al. (2013) Disentangling breast cancer patients' perceptions and experiences with regard to endocrine therapy: nature and relevance for non-adherence. *Breast (Edinburgh, Scotland)*. [Online] 22 (5), 661–666.

Wroe, A. L. (2002) Intentional and unintentional nonadherence: a study of decision making. *Journal of Behavioral Medicine*. [Online] 25 (4), 355–372.

Xu, L. and Wang, A. (2019) Health belief about adjuvant endocrine therapy in premenopausal breast cancer survivors: a qualitative study. *Patient Preference and Adherence*. [Online] 1519–1525.

Appendices

Appendix 1: Database Searches

PubMed search

The search history for PubMed database showing the queries constructed and the final yield

Search	Query	Items found
#1	Search ((((((((((((((((((((((((((((((Cancer) OR Tumor) OR Tumors) OR Chemotherapy) OR Oncology) OR Antineoplastic) OR Antineoplastics) OR Antineoplastic Drugs) OR Antitumor Drugs) OR Neoplasm) OR Neoplasia) OR Antineoplastic Agents) OR Anticancer Agents) OR Antitumor Agents) OR Cancer Chemotherapy Agents) OR Cancer Chemotherapy Drugs) OR Chemotherapeutic Anticancer Agents) OR Chemotherapeutic Anticancer Drug) OR Anti-Carcinogenic Agents) OR Anticarcinogenic Agents) OR Anti-Carcinogenic Drugs) OR Anticarcinogenic Drugs) OR Anticarcinogens) OR Cancer Therapy) OR Cancer Pharmacologic Therapy) OR Cancer Pharmacotherapy))) OR Tumour) OR Tumours) OR Antitumour Drugs) OR Antitumour Agents)	7021305
#2	Search ((((((((((((((((((((Adherence) OR Compliance) OR Nonadherence) OR Non-adherence) OR Noncompliance) OR Non-compliance) OR Medication Adherence) OR Medication compliance) OR Medication Non-adherence) OR Medication Non-compliance) OR Medication Nonadherence) OR Medication Noncompliance) OR Medication Persistence) OR Patient Adherence) OR Patient Compliance) OR Patient Non-adherence) OR Patient Non-compliance) OR Patient Nonadherence) OR Patient Noncompliance) OR Patient Cooperation)	293498
#3	Search ((((((((((((((((((Oral) OR Oral Administration) OR Administration, Oral) OR Administration, Oral Drug) OR Drug Administration, Oral) OR Oral Drug Administration) OR Oral Medicine) OR Medicine, Oral) OR Oral Medication) OR Medication, Oral) OR Tablets) OR Tamoxifen OR anastrozole OR exemestane OR letrozole OR hormonal therapy OR Hormone therapy OR Antihormonal therapy))) OR adjuvant endocrine therapy) OR Aromatase Inhibitor))	1685394
#4	Search (qualitative) OR qualitative research	219673
#5	Search (((**#1**) AND **#2**) AND **#3**) AND **#4)**	251

Cumulative Index to Nursing and Allied Health Literature (CINAHL)

The search history for the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database showing the queries constructed and the final yield

Search	Query	Search options	Items found
S1	Cancer OR tumor OR chemotherapy OR oncology OR neoplasia OR neoplasm	No limiters Apply all related words	3572944
S2	Adherence OR Compliance OR nonadherence OR noncompliance	No limiters Apply all related words	278895
S3	Oral	No limiters Apply all related words	652461
S4	Qualitative	No limiters Apply all related words	175291
S5	S1 AND S2 AND S3 AND S4	No limiters	28

Web of Science

The search history for the Web of Science database showing the queries constructed and the final yield.

Search	Query	Items found
1	((Cancer) OR (Tumor) OR (Tumour) OR (Tumors) OR (Tumours) OR (Chemotherapy) OR (Oncology) OR (Antineoplastic) OR (Antineoplastics) OR (Antineoplastic Drugs) OR (Antitumor Drugs) OR (Antitumour Drugs) OR (Neoplasm) OR (Neoplasia) OR (Antineoplastic Agents) OR (Anticancer Agents) OR (Antitumor Agents) OR (Antitumour Agents) OR (Cancer Chemotherapy Agents) OR (Cancer Chemotherapy Drugs) OR (Chemotherapeutic Anticancer Agents) OR (Chemotherapeutic Anticancer Drug) OR (Anti-Carcinogenic Agents) OR (Anticarcinogenic Agents) OR (Anti-Carcinogenic Drugs) OR (Anticarcinogenic Drugs) OR TOPIC: (Anticarcinogens) OR (Cancer Therapy) OR (Cancer Pharmacologic Therapy) OR (Cancer Pharmacotherapy))	2988499
2	((Adherence) OR (Compliance) OR (Nonadherence) OR (Non-adherence) OR (Noncompliance) OR (Non-compliance) OR (Medication Adherence) OR (Medication Compliance) OR (Medication Non-adherence) OR (Medication Non-compliance) OR (Medication Nonadherence) OR (Medication Noncompliance) OR (Medication Persistence) OR (Patient Adherence) OR (Patient Compliance) OR (Patient Non-adherence) OR (Patient Non-compliance) OR (Patient Nonadherence) OR (Patient Noncompliance) OR (Patient Cooperation))	259728
3	((Oral) OR (Oral Administration) OR (Administration, Oral) OR (Administration, Oral Drug) OR (Drug Administration, Oral) OR (Oral Drug Administration) OR (Oral Medicine) OR (Medicine, Oral) OR (Oral Medication) OR (Medication, Oral) OR (Tablets))	563987
4	((Qualitative) OR (Qualitative Research))	345645
5	#1 AND #2 AND #3 AND #4	29

PsycINFO

The search history for the PsycINFO database showing the queries constructed and the final yield

Search	Query	Items found
1	(Cancer or Tumor or Tumour or Tumors or Tumours or Chemotherapy or Oncology or Antineoplastic or Antineoplastics or Antineoplastic Drugs or Antitumor Drugs or Antitumour Drugs or Neoplasm or Neoplasia or Antineoplastic Agents or Anticancer Agents or Antitumor Agents or Antitumour Agents or Cancer Chemotherapy Agents or Cancer Chemotherapy Drugs or Chemotherapeutic Anticancer Agents or Chemotherapeutic Anticancer Drug or Anti-Carcinogenic Agents or Anticarcinogenic Agents or Anti-Carcinogenic Drugs or Anticarcinogenic Drugs or Anticarcinogens or Cancer Therapy or Cancer Pharmacologic Therapy or Cancer Pharmacotherapy)	74588
2	(Adherence or Compliance or Nonadherence or Non-adherence or Noncompliance or Non-compliance or Medication Adherence or Medication Compliance or Medication Non-adherence or Medication Non-compliance or Medication Nonadherence or Medication Noncompliance or Medication Persistence or Patient Adherence or Patient Compliance or Patient Non-adherence or Patient Non-compliance or Patient Nonadherence or Patient Noncompliance or Patient Cooperation)	54931
3	(Oral or Oral Administration or Administration, Oral or Administration, Oral Drug or Drug Administration, Oral or Oral Drug Administration or Oral Medicine or Medicine, Oral or Oral Medication or Medication, Oral or Tablets)	62288
4	(Qualitative or Qualitative Research)	153868
5	1 and 2 and 3 and 4	8

Wiley Online Library

The search history for the Wiley database showing the queries constructed and the final yield

Search	Query	Items found
1	(Cancer or Tumor or Tumour or Tumors or Tumours or Chemotherapy or Oncology or Antineoplastic or Antineoplastics or Antineoplastic Drugs or Antitumor Drugs or Antitumour Drugs or Neoplasm or Neoplasia or Antineoplastic Agents or Anticancer Agents or Antitumor Agents or Antitumour Agents or Cancer Chemotherapy Agents or Cancer Chemotherapy Drugs or Chemotherapeutic Anticancer Agents or Chemotherapeutic Anticancer Drug or Anti-Carcinogenic Agents or Anticarcinogenic Agents or Anti-Carcinogenic Drugs or Anticarcinogenic Drugs or Anticarcinogens or Cancer Therapy or Cancer Pharmacologic Therapy or Cancer Pharmacotherapy)	1241810
2	(Adherence or Compliance or Nonadherence or Non-adherence or Noncompliance or Non-compliance or Medication Adherence or Medication Compliance or Medication Non-adherence or Medication Non-compliance or Medication Nonadherence or Medication Noncompliance or Medication Persistence or Patient Adherence or Patient Compliance or Patient Non-adherence or Patient Non-compliance or Patient Nonadherence or Patient Noncompliance or Patient Cooperation)	488332
3	(Oral or Oral Administration or Administration, Oral or Administration, Oral Drug or Drug Administration, Oral or Oral Drug Administration or Oral Medicine or Medicine, Oral or Oral Medication or Medication, Oral or Tablets)	739894
4	(Qualitative or Qualitative Research)	1752053
5	1 and 2 and 3 and 4	8

ProQuest

The search history for the ProQuest database showing the queries constructed and the final yield

Search	Query	Items found
1	ti (Cancer OR Tumor OR Tumour OR Tumors OR Tumours OR Chemotherapy OR Oncology OR Antineoplastic OR Antineoplastics OR Antineoplastic Drugs OR Antitumor Drugs OR Antitumour Drugs OR Neoplasm OR Neoplasia OR Antineoplastic Agents OR Anticancer Agents OR Antitumor Agents OR Antitumour Agents OR Cancer Chemotherapy Agents OR Cancer Chemotherapy Drugs OR Chemotherapeutic Anticancer Agents OR Chemotherapeutic Anticancer Drug OR Anti-Carcinogenic Agents OR Anticarcinogenic Agents OR Anti-Carcinogenic Drugs OR Anticarcinogenic Drugs OR Anticarcinogens OR Cancer Therapy OR Cancer Pharmacologic Therapy OR Cancer Pharmacotherapy)	240030
2	ti (Adherence OR Compliance OR Nonadherence OR Non-adherence OR Noncompliance OR Non-compliance OR Medication Adherence OR Medication Compliance OR Medication Non-adherence OR Medication Non-compliance OR Medication Nonadherence OR Medication Noncompliance OR Medication Persistence OR Patient Adherence OR Patient Compliance OR Patient Non-adherence OR Patient Non-compliance OR Patient Nonadherence OR Patient Noncompliance OR Patient Cooperation)	316018
3	ti(Oral OR Oral Administration OR Administration, Oral OR Administration, Oral Drug OR Drug Administration, Oral OR Oral Drug Administration OR Oral Medicine OR Medicine, Oral OR Oral Medication OR Medication, Oral OR Tablets)	6598861
4	Qualitative OR Qualitative Research	2598442
5	**#1** AND **#2** AND **#3** AND **#4**	189

Appendix 2: Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ

Table illustrating compliance with the reporting guideline for qualitative systematic reviews: Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ

	Item	Guide and description	Included
1	Aim	State the research question the synthesis addresses.	x
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*	x
3	Approach to searching	Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved).*	x
4	Inclusion criteria	Specify the inclusion/exclusion criteria *(e.g. in terms of population, language, year limits, type of publication, study type).*	x
5	Data sources	Describe the information sources used (e.g. *electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists)* and when the searches conducted; provide the rationale for using the data sources.	x
6	Electronic Search strategy	Describe the literature search *(e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).*	x
7	Study screening methods	Describe the process of study screening and sifting *(e.g. title, abstract and full text review, number of independent reviewers who screened studies).*	x
8	Study characteristics	Present the characteristics of the included studies *(e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).*	x
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion *(e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).*	x
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).*	x

	Item	Guide and description	Included
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting)*.	x
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	x
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	x
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software)*.	x
15	Software	State the computer software used, if any.	x
16	Number of reviewers	Identify who was involved in coding and analysis.	x
17	Coding	Describe the process for coding of data *(e.g. line by line coding to search for concepts)*.	x
18	Study comparison	Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary)*.	x
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	x
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	x
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. *new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct)*.	x

Appendix 3: Categories and quotes

Categories	Quotes
The paradigm model for the category 'The treatment of breast cancer: prescription of a long-term drug'	
Causal conditions	
Transitioning into a new stage of breast cancer treatment	"I try to remember everything ... on the first day. But I can't remember anything when things happen. I really hope we can get the information gradually." Patient 5 Study 2 "I think we need a package of all the information. A pamphlet, an instruction book, or a supportive care website ... will be okay" Patient 2 Study 2 "I am afraid of receiving too much information. And I just need the information that encourages me and assures me that I'm still alive." Patient 8 Study 2 "Maybe he did tell me everything, but I also knew I wanted to live. I didn't want to take a chance on not doing what the doctor told me not to do" Study 3 "I would definitely recommend psychological support, especially in the first stage of the disease as it is terrifying" (interview 19) Study 5 "The doctor frightened me so much with all the possible side-effects that I asked myself, "Where are you going with this treatment?" Study 6
A sense of being overwhelmed by the received information	"I try to remember everything ... on the first day. But I can't remember anything when things happen. I really hope we can get the information gradually." Patient 5 Study 2 "I think we need a package of all the information. A pamphlet, an instruction book, or a supportive care website ... will be okay" Patient 2 Study 2 "I am afraid of receiving too much information. And I just need the information that encourages me and assures me that I'm still alive." Patient 8 Study 2 "Maybe he did tell me everything, but I also knew I wanted to live. I didn't want to take a chance on not doing what the doctor told me not to do" Study 3 "I would definitely recommend psychological support, especially in the first stage of the disease as it is terrifying" (interview 19) Study 5 "The doctor frightened me so much with all the possible side-effects that I asked myself, "Where are you going with this treatment?" Study 6
Fear of cancer recurrence	"I see my tamoxifen as the lifeline to being cancer free." Participant 27, age range 50–64, tamoxifen Study 1 "The way I see it is that this is my chance. It may be a small chance but I see it as being a chance to diminish my chances of its returning..." Participant 3, age range 50–64, letrozole Study 1 "...my body has already proved I can get breast cancer...if I've got to be on a tablet for 5 years that's going to put a protection around it, it hopefully won't happen again..." Participant 15, agerange ≤49, tamoxifen Study 1 "So I think I'm sure that's what they said that the surgery would cut it out, the radiotherapy would kill it externally although it did go in and the tablet, the anastrozole was to try and prevent the cancer cells reforming." Participant 21, age range ≥65,anastrozole Study 1 "My feeling towards the pill is that this is preventing the cancer from coming back. I'm putting all my hopes in, that tiny little pill is going to keep me well for the next five years." (P9) Study 15 "For 5 years I will take that tablet, because if it is the barrier between getting it and not getting it, I will take that tablet. I am adamant that I will take it for the 5 years. I will definitely take it for 5 years until they tell me to stop." (P1) Study 15 "When I was told I had breast cancer I thought 'right, this is it, I have three children at home, I want to be around for them for a lot longer'. I don't want the cancer to come back, I have all my faith in tamoxifen." (P24) Study 15
Fear of possible side-effects of the treatment	"Obviously at the beginning you are a little scared, even for the possible side-effects" (interview 10) Study 5 "The doctor frightened me so much with all the possible side-effects that I asked myself, where are you going with this treatment?" Study 6 "I saw on the Internet women with side-effects, terrible side-effects. It's scarring!" Study 6 "The doctor told me about the two main side-effects, and then he must have thought, "She is so frightened; there's no need to talk more about it with her"." Study 6
Lack of information and uncertainty about the medication (necessity, efficacy, safety and mechanism of action)	"One told you, "Take this," and this is it. No one explains . . . anything [to you]. One told you, "This treatment is to prevent recurrence." But eventually, you don't know why and how it could stop recurrence." Study 6 "I think the treatment kills all the metastases. I think, you know, I'm not so sure." Study 6 "My understanding is that this endocrine therapy globally stops all the body's hormones, like, hypophysis, the thing in the thyroid. Like, all hormones, you know?" Study 6 "The surgeon told me, after surgery: "I've removed everything; it's over. You don't have cancer anymore." Study 6 "Even if I know it is supposed to do me good, I still wonder, if it cures me on one side, is it not damaging me on the other side?" Study 6 "I consider [the treatment] as my enemy." Study 6 "The doctor told me: 'After radiotherapy you will have a hormone, an anti-hormonal treatment, since your cancer is hormone-dependent'. It must be the same system as the pill, but I do not really know how it works. I think it blocks hormones which are targeted to the breast at certain times of the cycle; it puts me in a state of menopause. I wonder whether they just do things by thinking 'if '." (P., aged 37, 3 months of treatment) Study 9 "I need my questions answered in whatever way that she [the oncologist] can statistically, because she can't say personally what's going to happen to me. And then I'm going to have to decide which [AET treatment] I want." Study 12

	"The physician only told me I had to take the AHT medication and that I didn't have any other choice than taking the AHT. She didn't say much about side-effects. She said that side-effects were different for every person and that I would find out." Study 17 "I didn't know anything about it. Really no one's sort of explained what it is. They just said tamoxifen will help stopping recurrence." (Arlene, 62, adherent) Study 18
Vulnerability	"the most important thing is to not feel alone...especially at the beginning because one feels lost" (interview 11) Study 5 "I have a lot to live for, be grateful for. . . . I just have to have my head catch up to that idea." Study 7 "I do not want to look at my husband or kids and see worry in their eyes. . . . That, I can't take." Study 7 "You just need a way to put this all in perspective." Study 7 "I need to take care of me, but, when you haven't done that so well, you do need some guidance. I don't know how to do it in a way that is meaningful to me. I feel sort of lost . . . abandoned. Who is going to help me figure this out? If I knew how to do it, I would have done it already." Study 7 "I know I need to not be that person I was, but who I will become? That scares me." Study 7 "I need a GPS. I need a nurse. . . . I'm afraid I will just not do the work I need to do to really be better." Study 7
Experiencing difficulties during the initial stage of the treatment (personal level, professional level or emotional level)	"I would definitely recommend psychological support, especially in the first stage of the disease as it is terrifying" (interview 19) Study 5 "I was in a trance, traumatized really, but, at this point . . . you're somehow supposed to be over it." Study 7 "I need to work with someone who could help me redefine who I am, what's important . . . really, in every aspect of my life." Study 7 "It's like your last infusion is ending, and you can see everyone thinks, 'OK, finally [you're] back to normal.' It feels like they are ready to pounce on you. I'm thinking, like, really, I need a minute. I've been to hell and back." Study 7 "Just as I was feeling ready to talk, no one was there to listen. Care changes; friends move on to the next big thing." Study 7 "Now that this fighting part is over, no one addressed this new me I am to become. [There is] no help navigating it." Study 7 "You know what they say, fake it to make it, but I'm a wreck on the inside." Study 7
Actions/interactions	
Having a consultation about the medication where it is prescribed	"I just accept what the doctor said, you know". Participant 11,age range ≥65, taking tamoxifen which was changed toanastrozole Study 1 "I suppose just because the consultant explained that that would be part of the on-going treatment and so because I'd gone through all the other bits, there was no real reason to then say I wasn't going to take letrozole". Participant 9, age range ≥65,taking letrozole Study 1 "...you get no benefit that you can see, you just have to take peoples word for it" Participant 24, age range ≥65, takingletrozole Study 1 "I mean because I understand in general terms what's going on and you know if I wanted to I could go and investigate you know become a complete nerd about letrozole and all the different you know, but basically because I trust the clinical advice I'm being given." Participant 23, age range 50–64, taking letrozole Study 1. "Maybe he did tell me everything, but I also knew I wanted to live. I didn't want to take a chance on not doing what the doctor told me not to do" Study 3 "It wasn't a choice at all. I mean they're professionals so I just listened to what they said." It wasn't a choice at all. I mean they're professionals so I just listened to what they said. (Barbara, 64, non-adherent) Study 18 "I wanted to know more about why I was taking it and he went into a lot of detail of how it works. [If my doctor says] it reduces the risk of the cancer coming back, I'd be mad not to take it. " P19 adherer] Study 19 "I must admit I take it – if they [doctors] say it's a good idea I'm very much […] I think because my experience has been so positive with them [doctors] I've not come away doubting anything." [P2 adherer] Study 19 "I just figured if [the doctor] wanted me to take it, I would at least give It a try." Study 20 "Just the sheer fact that the doctor tells you you gotta have it to live, you take It." Study 20 "I knew there was not an option that I was not going to take It. so I think It was just such a positive reinforcement when it was given to me, like this is what you do for five years to block the estrogen, and I just went with It. I didn't second guess it." Study 20 "I believe in my doctors, so if they tell me [taking AET] is the right thing to do, that's what I've got to do." Study 20 "Talking to my oncologist and my history of the cancer coming back, we talked about the tamoxifen and going on it. That's when I decided to go ahead and get back on." Study 20 "After talking to my oncologist [about my side-effects], because of my history of the fact that it was coming back, [we] talked about the tamoxifen and going on it. That's when I decided to go ahead and get on it." Study 20

	"Yes the doctor prescribed it to you, you trust him. It's like chemo treatment. It's preferable to not have it but you are told that you must." Focus Group 3, Participant J. Study 21
Patient accepting or deferring the treatment (dependent on e.g. patient trusting their healthcare provider advice, patient awareness of the necessity of the medication, the level of stability in family and social life, emotional stability and support, patient desire to continue living cancer free, patient co-morbidities, patient need of normalcy)	"Over this last year, I did everything I was supposed to. I have other worries I need to take care of before starting that." Study 7 "I owe so many people favours. They've had enough of me and my cancer. So have I." Study 7 "I'm a mother, I have a family, a job, and now any help or kindness I had over the past year, well, that's gone. Now it's back to me caring for others—something I do all too well and, in the process, forget me" Study 7 "I tried to act like nothing had happened. I dressed nice, did my makeup, all of it. I had to . . . for my family." Study 7 "I do not want to look at my husband or kids and see worry in their eyes. . . . That, I can't take." Study 7 "Everything in my life was on hold while I did this thing called the fight [breast cancer]. Now I need to get back to living but not the same way. That takes work." Study 7 "I need to work with someone who could help me redefine who I am, what's important . . . really, in every aspect of my life." Study 7 "Now that this fighting part is over, no one addressed this new me I am to become. [There is] no help navigating it." Study 7 "I need to take care of me, but, when you haven't done that so well, you do need some guidance. I don't know how to do it in a way that is meaningful to me. I feel sort of lost . . . abandoned. Who is going to help me figure this out? If I knew how to do it, I would have done it already." Study 7 "Just as I was feeling ready to talk, no one was there to listen. Care changes; friends move on to the next big thing." Study 7 "I was in a trance, traumatized really, but, at this point . . . you're somehow supposed to be over it." Study 7 "I thought I would be through after [primary treatment].… I was upset that it's going to drag on and on and on, but I do it." Study 14 "After the previous treatments, I wanted to put it out of my head and go on with my life. But when I buy new clothes, I have to buy a bigger size, which confronts me with that goddamn disease. I want to leave this chapter behind and be like before. I do not think I will ever be the same again, and that is very hard to accept." Study 17 "I worry . . . my weight, my lipids. . . . No one seems worried about my heart anymore." Study 7 "At my age [64 years old], for every year I take the pills, they say you get five years, so that takes me to 69. So, say I take them for two [years], is 74 reasonable? I think, given my family history of cardiac problems, that would be good. But cardiac problems, arthritis? No one seems to remember that anymore. You need it to be individual." Study 7
Patients taking care of them-selves	"Left to figure it out in their own." Study 7 "Now that this fighting part is over, no one addressed this new me I am to become. [There is] no help navigating it." Study 7 "I need to take care of me, but, when you haven't done that so well, you do need some guidance. I don't know how to do it in a way that is meaningful to me. I feel sort of lost . . . abandoned. Who is going to help me figure this out? If I knew how to do it, I would have done it already." Study 7 "And so, at that point, I'm done with my radiation, the chemo, with the surgery, with the whole deal. I'm kind of on my own a little bit.… You're also trying to get your footing…you feel like you don't have all the structures we talked about before, so now you're winging it, and that's scary." Study 14
Patients looking for information else-where (through specialized websites, specialized forums or from other patients)	"I look for information on my own...they just told me to take that drug because there was a 45% possibilities not to face other problems and nothing more! Then one compares and discusses with friends, on the Internet, and evaluates the effects that can be attributed to the drug" (interview 22). Study 5 "It would be good to receive more information from nurses" (interview 2) Study 5 "I saw on the Internet women with side-effects, terrible side-effects. It's scarring!" Study 6 "Left to figure it out in their own." Study 7 "clinical studies with the latest information" Study 12 "published studies" Study 12 "New research" Study 12 "one pill per day for five years" or "up to 10 years because of "new research." Study 12
Consequences	
Going along with the hormonal prescription	"I see my tamoxifen as the lifeline to being cancer free." Participant 27, age range 50–64, tamoxifen Study 1 "The way I see it is that this is my chance. It may be a small chance but I see it as being a chance to diminish my chances of its returning...". Participant 3, age range 50–64, letrozole Study 1 "...my body has already proved I can get breast cancer...if I've got to be on a tablet for 5 years that's going to put a protection around it, it hopefully won't happen again..." Participant 15, agerange ≤49, tamoxifen Study 1 "It shocks me because I felt the fear of God in me. I had to take this. I didn't ask the questions which is so unusual for me." Study 3 "My feeling towards the pill is that this is preventing the cancer from coming back. I'm putting all my hopes in, that tiny little pill is going to keep me well for the next five years." (P9) Study 15

	"For 5 years I will take that tablet, because if it is the barrier between getting it and not getting it, I will take that tablet. I am adamant that I will take it for the 5 years. I will definitely take it for 5 years until they tell me to stop." (P1) Study 15 "When I was told I had breast cancer I thought 'right, this is it, I have three children at home, I want to be around for them for a lot longer'. I don't want the cancer to come back, I have all my faith in tamoxifen." (P24) Study 15 "Well since the option is keep taking it or be dead, it's not much of a choice for me." (Vanessa, 63, adherent) Study 18
Delaying the hormonal treatment	"Over this last year, I did everything I was supposed to. I have other worries I need to take care of before starting that." Study 7 "I owe so many people favours. They've had enough of me and my cancer. So have I." Study 7 "I just keep refilling the prescription. . . . I said I was taking it. They seemed happy I had no symptoms. . . . I mean, I planned to start it, and I did. I just needed to get other [health-related] things in order, but after all they have done for me, I could never just say I didn't start yet. As I am saying this to you, I know how crazy it sounds. I could not imagine what it would be like for them to hear me say it." Study 7
Transitioning into the long-term treatment phase with ease (trusting the treatment and finding the necessary support)	"I see my tamoxifen as the lifeline to being cancer free." Participant 27, age range 50–64, tamoxifen Study 1 "The way I see it is that this is my chance. It may be a small chance but I see it as being a chance to diminish my chances of its returning...". Participant 3, age range 50–64, letrozole Study 1 "...my body has already proved I can get breast cancer...if I've got to be on a tablet for 5 years that's going to put a protection around it, it hopefully won't happen again..." Participant 15, agerange ≤49, tamoxifen Study 1 "It shocks me because I felt the fear of God in me. I had to take this. I didn't ask the questions which is so unusual for me." Study 3 "My feeling towards the pill is that this is preventing the cancer from coming back. I'm putting all my hopes in, that tiny little pill is going to keep me well for the next five years." (P9) Study 15 "For 5 years I will take that tablet, because if it is the barrier between getting it and not getting it, I will take that tablet. I am adamant that I will take it for the 5 years. I will definitely take it for 5 years until they tell me to stop." (P1) Study 15 "When I was told I had breast cancer I thought 'right, this is it, I have three children at home, I want to be around for them for a lot longer'. I don't want the cancer to come back, I have all my faith in tamoxifen." (P24) Study 15 "Well since the option is keep taking it or be dead, it's not much of a choice for me." (Vanessa, 63, adherent) Study 18
Having difficulties transitioning into the long-term treatment phase	"Over this last year, I did everything I was supposed to. I have other worries I need to take care of before starting that." Study 7 "I owe so many people favours. They've had enough of me and my cancer. So have I." Study 7 "I just keep refilling the prescription. . . . I said I was taking it. They seemed happy I had no symptoms. . . . I mean, I planned to start it, and I did. I just needed to get other [health-related] things in order, but after all they have done for me, I could never just say I didn't start yet. As I am saying this to you, I know how crazy it sounds. I could not imagine what it would be like for them to hear me say it." Study 7
Being well informed by receiving the correct information (not looking for information in the wrong places and correcting the misconceptions about the treatment)	"I reached the conclusion [to take AET] with the doctor's help, of course". Study 12 "I suppose just because the consultant explained that that would be part of the on-going treatment and so because I'd gone through all the other bits, there was no real reason to then say I wasn't going to take letrozole." Participant 9, age range ≥65,taking letrozole Study 1 "I mean because I understand in general terms what's going on and you know if I wanted to I could go and investigate you know become a complete nerd about letrozole and all the different you know, but basically because I trust the clinical advice I'm being given." Participant 23, age range 50–64, taking letrozole Study 1 "I knew there was not an option that I was not going to take It. so I think It was just such a positive reinforcement when it was given to me, like this is what you do for five years to block the estrogen, and I just went with It. I didn't second guess it." Study 20 "It [AET] was strongly recommended because I was in a risky age group. I had just turned 40. And then, because my cancer was hormone sensitive and very reactive . . ." Individual Interview, Participant B. Study 21
Being wrongly informed about the medication (side-effects, mechanism of action, efficacy and safety)	"I look for information on my own...they just told me to take that drug because there was a 45% possibilities not to face other problems and nothing more! Then one compares and discusses with friends, on the Internet, and evaluates the effects that can be attributed to the drug" (interview 22). Study 5 "Education is necessary in order to understand the importance of it all" (interview 20) Study 5 "I consider [the treatment] as my enemy." Study 6 "Even if I know it is supposed to do me good, I still wonder, if it cures me on one side, is it not damaging me on the other side?" Study 6 "I saw on the Internet women with side-effects, terrible side-effects. It's scarring!" Study 6 "I think the treatment kills all the metastases. I think, you know, I'm not so sure." Study 6 "One told you, "Take this," and this is it. No one explains . . . anything [to you]. One told you, "This treatment is to prevent recurrence." But eventually, you don't know why and how it could stop recurrence." Study 6 "More information is needed to improve patients' choices" (interview 14) Study 5

	"I need my questions answered in whatever way that she [the oncologist] can statistically, because she can't say personally what's going to happen to me. And then I'm going to have to decide which [AET treatment] I want." Study 12
Less hospital visits (less communication with healthcare providers)	"Left to figure it out in their own." Study 7 "Now that this fighting part is over, no one addressed this new me I am to become. [There is] no help navigating it." Study 7 "I need to take care of me, but, when you haven't done that so well, you do need some guidance. I don't know how to do it in a way that is meaningful to me. I feel sort of lost . . . abandoned. Who is going to help me figure this out? If I knew how to do it, I would have done it already." Study 7 "And so, at that point, I'm done with my radiation, the chemo, with the surgery, with the whole deal. I'm kind of on my own a little bit…. You're also trying to get your footing…you feel like you don't have all the structures we talked about before, so now you're winging it, and that's scary." Study 14
Treatment refusal	
Fear of the potential side-effects	"I don't take everything they give me." "If it has too many side-effects, I don't take it." FGA Study 8 "I didn't take anything because I was afraid of the side-effects" FGB Study 8 "Most importantly, I read that tamoxifen causes cancer of the uterus. The contraceptive pill? I never took it because it was said to be carcinogenic. The hormone treatment for menopause? I did not agree to taking it either, for the same reason. Cancer I already had it once, and that was enough, so I refused to take tamoxifen!" (C., aged 56, refused tamoxifen) Study 9 "My main reasons for not taking it were the side-effects that you read about, you're straight in to a medically induced menopause. The mood swings, depression and I would be afraid that you would get hooked on medication, there's so many people out there being overly medicated." (P23) Study 15 "There's no nice way of telling somebody, they are the side-effects, but when someone says it to you, risk of clotting, effects your bone density, all that kind of stuff, you just think 'well I don't think I'll be bothered with that really." (P19) Study 15 "The effect may not be so obvious, and the medicine can lead to serious side-effects, such as uterine cancer, vaginal bleeding. I was frightened by these side-effects, so I didn't dare to take the medicine." Study 24
having other priorities	"I had a girlfriend, who helped me during the disease. She had kidney cancer 4 years ago while she was pregnant. She had a splendid baby, and no longer had cancer. It's a bit mysterious, cancer, isn't? After the disease, my husband and I had to go ahead. We thought: 'If that is the case, there's no point in taking tamoxifen and wasting five years. Tamoxifen did not seem vital to me, nor very reliable. Our wish to have a child was very strong, we did not agree with waiting." (C., aged 35,pregnant, refused tamoxifen treatment 3 years ago)Study 9 "I feel Tamoxifen wouldn't have suited my lifestyle to try and do what I have to do every day. It's fairly hard, when you're on a time schedule with a job and you have your targets to reach in the day at a certain time. I just wanted a quality of life for myself, even if I was only to get the last year the way I've got it, being medication free, for me personally it would have been a better quality than having to take it. (P23) Study 15 "Well that was my big thing about taking Aromasin If I have to take it for 5 years and my quality of life is so bad, do I want to take it? These are probably the last good 5 years of my life I'm 60 Do I take it and have all these side-effects?" Study 3 "I feel Tamoxifen wouldn't have suited my lifestyle to try and do what I have to do every day. It's fairly hard, when you're on a time schedule with a job and you have your targets to reach in the day at a certain time. I just wanted a quality of life for myself, even if I was only to get the last year the way I've got it, being medication free, for me personally it would have been a better quality than having to take it. (P23) Study 15 "I feel I would have been on Tamoxifen for five years, old before my time. I would be drugged up to the eyeballs from now until…forever." (P23) Study 15 "If I have to take something I wanted something that doesn't interfere with my level of functioning as much as possible. I said feck it, you want the best quality of life and you want to be able to live your life as normal as possible. " (P19) Study 15 "I don't want to live in this place where I feel that the medical model has me by the scruff of the neck. I think when you're diagnosed with cancer, you do become a victim for a while because you are in the clutches of the medical model and that's where you need to be. But there comes a time when you're done with your surgery and your radium and then its starts to be the treatment going forward, where you have to take back your choices for quality of life. I went for the best quality I could really for whatever will be remaining for me hopefully. The best commodity I have here now is time so how am I going to use it?" (P27) Study 15 "You go in with your mind made up you don't want to take it, and why you don't want to take it, because I want to stay as healthy as I can for as long as I can. It's not for me. I don't even want to try it for three months and come off it, because it would be in my system then, it's going to start closing everything down." (P23) Study 15 I was so scared, so I didn't take it, because I haven't had a child yet. I'm afraid I would not have a baby if I took the medicine. To be frank, I am already sick. If I am unable to have a child, I'm afraid my husband would divorce me. (P11) Study 24
Given the choice to stop	"If the results came back from the oncotype test to say that I had a high risk aggressive cancer I would have been on it straight away. Also I don't have the genetic cancer gene. That's how I weighed it up, those two things. I said right they're not getting any medication in to me. It was up to me then how I was going to handle it rather than it handling me, and that's the way I looked at it." (P23) Study 15

	"The doctor told me to take the medicine, but I think the surgery went very well, and it is not necessary to take medicine, so I did not take it." Study 24
Exhaustion from the initial stage of the treatment	"What I really thought was I don't think I want this. That's what I was thinking. I think mainly it's that I wanted to be finished with the treatment, I'd had the operation, I'd had the chemo, I had the radiotherapy but I just wanted to finish with it. As far as I was concerned that was the end of it. I didn't want to be still caught into the system." (P2) Study 15
Influenced by someone else's bad experience	"A cousin of mine was taking hormone therapy for breast cancer and ten years later the cancer came back in the other breast. So what did she achieve? Nothing. I know women eight, ten years down the line that are not taking it and they're fine." (P19) Study 15 " I did hear through different groups, through listening to other people's stories, that most of the people that had taken it below fifties didn't have a very high success rate with it. One was terminally ill, my own sister she was dead at 39 and another lady's daughter died around 41 and all three were on Tamoxifen, so that made up my mind." (P23) Study 15 "My friend died of breast cancer. She'd a similar surgery as my own, the chemo, the radiotherapy and all that. She gave up the medication and went alternative instead. She got 6 or 7 years so if I get to 70 that's alright you know. That's the way I feel about it, who knows after that." (P2) Study 15
The paradigm model for the category 'The treatment of breast cancer: adhering to the long-term treatment'	
Causal condition	
Wanting to continue living cancer free (necessity of the treatment)	"No, it's a religion, you know, it's I have my little blue box of pills that's counted out every day and it's in there" Participant 13, age ≥65,anastrozole Study 1 "Never missed it, never, it's in my head you know it's something I have to do" Participant 21, age range ≥65, anastrozole Study 1 "Well, I wouldn't forget my anastrozole, that's for sure, it's like my best friend" Participant 11, age range ≥ 65, taking tamoxifen which was changed to anastrozole Study 1 "I'm going to take my medication, regardless I mean I'm just going to take it I'm convinced that taking it for five years with the other therapies that I've had increases my survival rate up to ten years, but having talked to other women who have quit, they just really couldn't get past the symptoms and I understand that" Study 3 "As for the tablet, I now accept it, always hoping that everything will be fine." (interview 7). Study 5 "I am certain that I have done all the right things. . .after all, it is true that it makes me aware of the situation, but it does so by making me aware of the past and also the present and the future..." (interview 18) Study 5 "It's as if it acts as a protection cover. . .now I take it and I hope it works. . .it protects me. (interview 10) Study 5 "The tablet, I take it. . .also because fear is fear and I have a son to raise" (interview 7). Study 5 "These medicine are beneficial on the one hand and harmful on the other, but they help us to live longer and it is important to be aware that this is a medicine that helps to live. . .that's why one must take it. . .one must fight until God gives us the possibility" (interview 20) Study 5 "You learn to live with it...as it could save my life" (interview 22) Study 5 "I must admit that now talking about the disease, it is as if it has been defeated... I already feel almost entirely healed..." (interview I7) Study 5 "I'm living the therapy peacefully, one manages it with serenity. I live everything with great naturalness and serenity and I can manage everything very well" (interview 3) "I have to take this treatment if I want to live If I didn't take it, I would be six feet under" Study 6 "Finally, as long as I take it, I feel protected" Study 6 "I have many circulation problems and I have gained weight, that's true But maybe these things cannot all be attributed to the treatment We know there are phases in life, physical changes that occur at menopause, and well, we have to accept it You have to tell yourself: 'you are not 20 any more!' I will be 50 years old in a few days, that's not easy to acceptWith the disease that has added on 2 or 3 years, it's even more difficult But in the end, the side-effects, I guess once you have accepted them, you feel better! I feel the way you cope with this treatment is part of the treatment" (E, aged 49, 2 years of treatment) Study 9 "I still take it. I still take it... if I thought that the medication was going to make me have early onset dementia, I would think about it more, and I do know there've been some thoughts about that, but I still take it. I don't want to, (lowers tone) get breast cancer again, so, I take it." Study 11 "I'm taking it to keep the boogie man away." Study 11 "to keep "loose cells [from] travelling where they shouldn't." Study 11 "That's very important, that pill... I want to live... I want to stay healthy." Study 11 "I was conscious of saying, "Okay, do your job in there, Arimidex_ ."... it was a funny thing. I didn't experience that in the first year and maybe only because I was experiencing those other things [side-effects]. But, there was this short period of time where I'd take my water, drink it down and say, "Okay, do your thing, Arimidex_ , get in there, kill any cells that you see..." Study 11 "To me, the benefit of not getting cancer, whether it's breast or some other site, is certainly more advantageous than putting up with a little bit of wrinkles or some other problem... but on the other hand, you wonder" Study 11

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	“I still take it. I still take it... if I thought that the medication was going to make me have early onset dementia, I would think about it more, and I do know there’ve been some thoughts about that, but I still take it. I don’t want to, (lowers tone) get breast cancer again, so, I take it.” Study 11 “I’m taking it to keep the boogie man away.” Study 11 “to keep “loose cells [from] travelling where they shouldn’t.” Study 11 “That’s very important, that pill... I want to live... I want to stay healthy.” Study 11 “I was conscious of saying, “Okay, do your job in there, Arimidex_ .”... it was a funny thing. I didn’t experience that in the first year and maybe only because I was experiencing those other things [side-effects]. 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Fear of cancer recurrence (anticipating regret)	"I'm still alive but there's huge consequences that I live with every day and the knock-on effectmakes it really difficult and, you know, if you were to ask me, would I still going back, would I still go on tamoxifen? Absolutely because I wouldn't risk cancer coming back" Participant 26, age range 50–64, tamoxifen Study 1 "Okay, I have a choice: I either continue this medicine and know the side-effects or I stop taking this medicine and know that there's always a chance I'm going to get the cancer back I think that's what it is You just know this medicine has side-effects and you take it for what it's worth" Study 3 "1 still feel like I have the disease, even though it has been a year since surgery and 6 months since the start of hormone therapy. While I feel so lucky knowing that everything went well, the presence of the disease still lingers on. . ." (interview 15) Study 5 "I am afraid we won't succeed to make it go away I'm sorry, but it's true" Study 6 "Not taking [the treatment] is a terrible thing to do because you feel protected by it You say, "If I don't take it, what will happen?" Study 6 "I'm so afraid to forget it; I feel the fear in my stomach" Study 6 "I'm afraid to forget it I said to myself, "Am I going to do a stupid thing? And what if I take a double dose?" Study 6 "It is an anti-hormone, which prevents cancer recurrence I think it removes hormones from women, right? When you've had this disease, it is terrifying to think that it may happen again! Sometimes I woke up at night and I thought: 'I'm not going to die, damn!' So when I was told that my cancer was hormone-sensitive, I just took tamoxifen That's it" (B, aged 48, 30 months of treatment) Study 9

	“I still take it. I still take it... if I thought that the medication was going to make me have early onset dementia, I would think about it more, and I do know there’ve been some thoughts about that, but I still take it. I don’t want to, (lowers tone) get breast cancer again, so, I take it.” Study 11 “I’m taking it to keep the boogie man away.” Study 11 “to keep “loose cells [from] travelling where they shouldn’t.” Study 11 “That’s very important, that pill... I want to live... I want to stay healthy.” Study 11 “To me, the benefit of not getting cancer, whether it’s breast or some other site, is certainly more advantageous than putting up with a little bit of wrinkles or some other problem... but on the other hand, you wonder” Study 11 “I have been very open about my breast cancer. This encouraged the people around me to also talk with me about breast cancer. I got many warm reactions. The chemotherapy made me very ill, but it went away. 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But on the other hand I don’t want to take the risk because if you go against the professional maybe if you get sick again they’re going to say oh hold on, we told you to do this but you didn’t and now there’s no point complaining.” (P5) Study 15 “I want to take it because I want to keep the cancer away, I want to live. I’m just doing everything that I can to kind of keep it away.” (P22) Study 15 “There are parts of me where I am dying to finish tamoxifen to see if I feel a bit normal again. But I just kept that focus that, I really don’t want this to come back especially when I've two young children, I can put up with bone pain. I want to feel for myself that I gave this hundred percent.” (P14) Study 15 “No matter what comes along can’t be any worse than getting cancer, so I would still take it, unless it is life threatening, which most of the side-effects aren’t.” (P1) Study 15 “I’ve often thought ‘how am I going to stick this for another four years?’ but I don’t think I’d have the will to go through it again if it came back. It’s like, having a baby, your first time you don’t know, the second time you’re terrified because you know what you’re going in there for.” (P18) Study 15 “It's pointless coming off the tamoxifen because if it did ease the pain, would I say to myself well I don’t want to take it because it's making the pain worse, where I'm focused on the big picture of don’t wanting the cancer to come back.” (P14) Study 15 “I don’t want to go back again so that’s why I take the medication on a regular basis and I make sure I don’t forget. If you were in my position I think you would do the same thing to survive. I hope to god I never have to go through this again. (P5) Study 15 At this stage I don’t think anything would really happen if I stopped, but at the same time it is not a risk I want to take. (P8) Study 15 “After taking tamoxifen for 3 years, I was diagnosed with endometrial hyperplasia through ultrasound examination. Considering that I am at a higher risk of recurrence, my doctor prescribed 5-year hormonal therapy. Endometrial hyperplasia is milder than cancer recurrence. For this reason, I take the medication regularly because recurrence means death. “(46 years old, 35 months) Study 16 “The AHT is a protection against cancer. I think it will be hard for me the day I have to stop the medication. Suppose I relapse when I am no longer taking that medication. Now the medication gives me the feeling I am protected against recurrence. Study 17 “I know I have no other choice than taking the AHT medication. It protects me against cancer and we can be reasonably sure that there will be no relapse if I take this medication for five years. I have to continue now because there is always a little voice that says: “You have had cancer”.” Study 17 “Whether like you say with me it would have come back, I just don’t know. I’d rather take it than not.” (Ellen, 50, adherent) Study 18 “[taking tamoxifen] makes me feel better as well, because I feel like I am doing something actively to prevent it.” (Joanna, 46, adherent) Study 18 “Taking tamoxifen just kind of pales into insignificance and it seems like a very small price to pay for not getting breast cancer again.” (Katie, 56, adherent) Study 18 “I never stopped taking it because I thought the nausea and things like that, come on its keeping you alive so stop moaning.” (Michelle, 77, adherent) Study 18 “I’d be too frightened to be honest not to take it.” (Lauren, 62, adherent) Study 18

	"If it was for anything else other than the cancer I would have stopped it, there's no questions, but because of the cancer is such a big thing, you know the possible return of it, that's the only reason I'm struggling with it" (Celia, 67, non-adherent) Study 18 "But it's like you're damned if you do and you're damned if you don't. It's that worry if you don't take it, oh god, if they find something again then I think it's because I didn't take the tamoxifen. But on the other hand it's living with all these side-effects on it." (Kate, 52, nonadherent) Study 18 "When I don't take it I think oh, god, I should be taking it. I just feel so guilty when I don't take it, but I do feel better when I'm not on it." (Kate, 52, non-adherent) Study 18 "I find it very difficult to be honest. . .I think the thing is anything that you find that you feel that is not right in your body then you start thinking 'I wonder if it's something serious'." (Arlene, 62, adherent) Study 18 "That would be my biggest fear is, it's not, I suppose if it's going to come back it's possibly when, but I can't live my life like that. So I kind of like have to block it and just continue as much as I can." (Elisabeth, 37, adherent) Study 18 "Someone said to me it's like having a sword dangling above your head, and it is. You just feel like tomorrow you don't know what's going to happen. It's always there in the back of your mind." (Kate, 52, non-adherent) Study 18 "I can never know what the right answer is, because I don't know whether the cancer will come back. I can't know until it happens." (Celia, 67, non-adherent) Study 18 "I will carry on despite how I feel just because it's the only thing I can do and I'll do anything I can because of the kids really – I do want to be around" [for them]. [P1, adherer] Study 19 "[…] [my mother's] trouble started up again when she stopped the tamoxifen so I have got that double idea that I'm safe while I'm on it." [P12 adherer] Study 19 "I just felt like this was what I had to do to keep the cancer from coming back, and I'll do what I have to do." Study 20 "I mentioned it to [my doctor], but I knew it was just one of those things I would have to cope with, so I just did." Study 20 "Well, the only thing l can think of [that was an important benefit] is that I have a process in mind that I'm not gonna get [cancer] anymore. That's the way I feel, that I'm here because of a reason, that l have a lot of things to do. I have a new granddaughter that I want to continue being with her. I know I'm not gonna get cancer." Study 20 "The advantage they told me, was that it could save me. [. . .] I saw this as prevention against a recurrence." Individual Interview, Participant E. Study 21 "If the hot flashes are to help me stay alive, then I'll just turn down the heating system." Focus Group 3, Participant Z. Study 21 "If I don't take it I feel a bit guilty. I mean to say that if my cancer comes back, I'll say well there, you didn't follow it." Individual Interview, Participant H. Study 21 Being on these pills you start to forget what it's for. It's just like taking another pill, but when you get some of the symptoms, when they start to flare up, then it reminds you of actually what you're doing. And then you kind of have to go back into the fight mode again and say, 'Okay, this isn't going to kill me.' (AET persistent) Study 23
Receiving the correct information about the treatment and side-effects in advance	"Sometimes I am not sure if it is normal, bad or very serious Sometimes I knew that it was not normal when my hands and feet were numb But I was still not sure if I should wait until the next doctor's visit (or see a doctor immediately)" Patient 3 Study 2 "I didn't expect the night sweats to be so bad I didn't expect them to interfere with my sleep" Study 3 "I wouldn't have ever thought that it would interfere so much that I don't feel like myself I don't have the energy I can't sleep I'm having trouble at work" Study 3 "What'll help is taking the load off the oncologist, because their days are so busy And when you know they're dealing with people that are sick and going through treatment and we need someone to discuss these things now (symptoms)" Study 3 "There has to be somebody helping us with those things Why am I going off of this [AET] in 5 years? We need a theory about what this Arimidex is doing to us I worked in the medical field I really don't understand It stops estrogen, ok, that's all I know I think that would really be helpful to help people understand why they're taking it (symptoms)" Study 3 "And she [a nurse] told me, she said yeah that's Tamoxifen That's one of the side-effects So I told her wow, …I never knew…Because the first time when I was on the Tamoxifen, it's like sometimes I would be in a rage" Study 4 "I was on crutches I was using a cane I couldn't get out of a chair because my knees were so bad I mean they still are, but they're 100 % better, and it's been a year and a half, and I went on a site called askapatientcom I read case histories from age 37 to 73, who had been on just Arimidex, and I was blown away at how many women have suffered this knee problems… And so… I Googled Arimidex and started to read about it… I mean I have a folder that's probably this thick about it It's nasty It's terrible stuff" Study 4 "Well you need to know the side-effects, that's the first thing because you want to know how you can pace your day and what to expect throughout that day and what to do" Study 4 "If we have side-effects, it is for the doctor to say what to do I'm not capable of knowing what to do" Study 6 "There is far more information than I need All I want to know is a few simple things— am I going to get nauseated? Am I going to be able to drive?" FGA Study 8 "I guess I didn't expect to feel as weak." Study 10 "But see, somebody needs to educate you on your medication." Study 10

	"Just before I started using endocrine therapy, I got a brochure and I read it carefully. I don't think I discussed the information of the brochure with my oncologist. I spoke with him later when I was already using it and experienced side-effects. I have a need to gain knowledge you know. When I am concerned about something, I'll try to find information about my concerns and if at that point I do not understand the information I ask my oncologist or primary care physician. However, my primary care physician often needs to consult my oncologist, so that does not work out very well." Study 13 "It is not difficult for me to swallow this small tablet or to remove it from the blister. I take it just before retiring to bed with a bit of water. I have never forgotten to take it. The osteoporosis tablet on the other hand is much bigger and awkward to swallow. Fortunately, I only need to take that tablet once a week. I am not sure how long I will have to use Arimidex." Study 13 "People (clinicians) aren't very forthcoming about telling you that information, you have to, you gather all the information as you go along yourself. But I'd be very fussy anyway, I'd want to know the in's and out's of everything." (P19) Study 15 "They could have gone through some basic information about the effects of it and what might happen if I didn't take it. I like information. I gather information, it clarifies things for me. I don't like to be in a bit of a morass. Because then you say, who actually knows anything here? And you do expect the professionals to know. At least to give you that bit of information and then you can at least make your decision around something that's been clarified." (P2) Study 15 "Nobody tells you well if you do go on it there's risks here that this could happen to you, you do read a little bit about that but their minimised. I think that's to tilt it in favour of going on it. We don't hear enough about the side-effects not enough that people talk about it. Because people feel very grateful to be a survivor so it's that whole thing nobody tells you how pregnancy and delivery is until you're in it, it's that whole conspiracy of silence." (P27) Study 15 "I read the patient information leaflet and look for testimonials on the internet from women who have the same side-effects as I have. When I find an answer, I feel reassured. I regret I do not find reassurance and answers with my physician." Study 17 "I think they have explained too little about side-effects. They have actually minimized them, which makes them worse than I imagined them to be. Now I have to learn to deal with it after I have experienced them and this is very difficult." Study 17 "I was prepared for anything, except the fact that I would go into menopause from one day to the next. Nobody had informed me about it. I was very, very disappointed and saddened. People say it had to happen, which is true, but that was the furthest thing from my mind. You are losing part of your femininity. For me that was the most difficult part of the entire treatment. . . I did have everything, but that was the worst for me. And maybe because they did not inform me in advance." Study 17 "But it's like you're damned if you do and you're damned if you don't. It's that worry if you don't take it, oh god, if they find something again then I think it's because I didn't take the tamoxifen. But on the other hand it's living with all these side-effects on it."(Kate, 52, nonadherent) Study 18 "I think there should be more help, psychologically, with side-effects of tamoxifen. I think people ought to be warned." (Kate, 52, non-adherent) Study 18 "I would like there to be more help for people who get this extreme fatigue, whether it's from the radiotherapy or tamoxifen." (Celia, 67, non-adherent) Study 18 "I would have liked more information to prepare for the side-effects. I was given lots of information about the side-effects of chemotherapy and how to manage them, but I wasn't expecting the side-effects of AET. So perhaps that made it worse." [P1 adherer] Study 19 "I thought it was the long-term effects of chemotherapy, so I thought it would improve. When it didn't long-term, I began to realise it was possibly the hormone therapy. [P17 adherer]" Study 19 "I am sure I'd been told but you are suddenly bombarded with so much information. Not that people mean to do that but there is a lot to contend with at a time when you are not really taking it in." [P21 nonadherer] Study 19 "If someone had said to me, these are the side-effects that other women report – say 20% of women have this side-effect, and if you get it come back and we can help you with it, then that would have been great. It's a lack of information that's the problem." [P26 nonadherer] Study 19 "Don't get me wrong. My GP is lovely. But they don't know much about treatments for breast cancer. I'd rather talk to someone at the hospital." [P22 nonadherer] Study 19 "They are cautious with the amount of information they give you. You can tell they are not telling you everything. I can understand why they do this, but I would have preferred more information." [P31 nonadherer] Study 19 "They answer questions but very much within their own confines. [P27 nonadherer] Study 19 "I didn't even know my body was going to go through that. It hit me like a boom." Study 20 "[My doctor] told me I would probably have night sweats and hot flashes, but that's all I really expected. I didn't expect the [severe side-effects] I had. … It started with pain in my shoulders, and then it moved to my jaw. Eventually, it moved to every joint in my body." Study 20 "I had tons of questions and I wasn't able ask them because she [oncologist] was, I felt that she was anxious, busy, it seemed as though I had to go quickly. So I was left with my questions." Individual Interview, Participant K. Study 21
Fear of the treatment and its side-effects	"I'm very afraid of this treatment I'm scared" Study 6 "I've never taken the pill, because I have never been able to bear hormonal treatment, it made me sick With tamoxifen, I was expecting it to be disastrous because I thought it would be like taking the pill, vomiting all the time, bleeding problems, etc But for the moment it seems to be OK" (P, aged 37, 3 months of treatment) Study 9

	"I heard the word hormone, and I was shocked I do not like this word It frightens me a little, hormonal treatment, I wonder whether we are not over medicated 'I am not sure it is really necessary" (P, aged 37, 3 months of treatment) Study 9 "It is a treatment which is tiring, ageing, and at the same time, you say: Well, it saves your life [Silence] It is a very peculiar situation Paradoxical" (E, aged 54, 4 years of treatment) Study 9 "This is controlling one thing and you have to have your side-effects. You have to take the good with the bad, you have to accept it." (P16) Study 15 "I'd rather put up with the bone pain and the cystitis and hot flushes than having to go through chemotherapy again and surgery. I just think you weigh it up. I do think definitely, the benefits outweigh the negatives on it, for me." (P14) Study 15 "I did not take a tablet before I got cancer. If I had a flu somebody would arrive home with an antibiotic, I didn't take it. I found it very tough to go on a tablet regime but something in my instinct just told me you need to take this tamoxifen. I knew people that would have had addictions to prescription tablets. I just found the whole thing of taking tablets, even today if I could just throw that bag out the window and say, no I don't have to take them anymore." (P7) Study 15 "While I'm on this Tamoxifen, it's always a worry, it's always at the back of my mind, I suppose it's like any drug. I had heard negative things about it, they said it causes ovarian cancer and things like that. (P17) Study 15 "It was a big deal that I had to take this tablet. When I first took it I'd have palpitations after taking it and I would be sitting waiting for it to do something else and after two hours was up, it's grand, I didn't die that time, I didn't take a heart attack. I still hate taking them, but it's not doing that anymore now. I'm aware that I have to take it. I know my body needs the tablet." (P3) Study 15 "I understand what it does. The benefits of tamoxifen are that I'm alive, despite all the side-effects. I suppose if I didn't have such a strong view that it's keeping me alive then it might be different." (P7) Study 15 "I'm aware of its pros and cons. But its pros far outweigh the cons. I'm aware of the dangers also of taking it and of not taking it. I'm worried about what if it gives me stomach cancer. What if I get clots, what if it starts messing round with the heart? I did think that I would end up in hospital with side-effects. But I don't like to get too far into it because I would come to a complete standstill and stop. In my head I'm safe when I take it." (P3) Study 15 "The benefits of taking it would outweigh the problems, the anxiety and the joint pains and stuff like that because I can manage those. If it means that I'm having a better chance of not getting breast cancer in me other breast. I'm happy that it is keeping me safe, even if it is not keeping me comfortable." (P8) Study 15 "It [tamoxifen] is horrible. It really is the most revolting tablet I've ever had to take." (Kate, 52, non-adherent) Study 18 "I worry more, not about the recurrence, but occurrence in a different part of my body due to this drug that I'm taking." (Miriam, 41, non-adherent) Study 18 "It is a hard drug to take because of everything it does. You think tamoxifen's done that, and I do blame it for a lot of things." (Kate, 52, non-adherent) Study 18 "If it was for anything else other than the cancer I would have stopped it, there's no questions, but because of the cancer is such a big thing, you know the possible return of it, that's the only reason I'm struggling with it" (Celia, 67, non-adherent) Study 18 "But it's like you're damned if you do and you're damned if you don't. It's that worry if you don't take it, oh god, if they find something again then I think it's because I didn't take the tamoxifen. But on the other hand it's living with all these side-effects on it." (Kate, 52, nonadherent) Study 18 "I have to say that my very first reaction on discovering I had the sort of breast cancer that needed more than surgery was, 'I don't want to take Tamoxifen'. I was prepared for everything else. But, I really, really was upset about the thought of taking Tamoxifen. I was devastated. I didn't want to take something that was such a long-term thing. I knew I didn't want to take it, but I knew I had to take it." (AET non-persistent) Study 23
Need of knowledge vs preference of ignorance	"I tend to put my head in the sand if there's any heavy duty so that's why I've never had the conversation this is your percentage of survival, if you take it, if you don't take it. Sometimes I don't want to ask something that I mightn't like the answer to. Because then you've to go home with that. So that's why I limit what I want to know." (P7) Study 15 "I suppose it's mad that I've put my trust in a doctor and a drug that I probably should know more about but the problem is I would have worried myself sick if I knew all of the bad things." (P17) Study 15 "I don't want to know side-effects of things. I was bombarded with a little bit too much stuff I didn't want to know. They're telling you, you have to know these things but I don't. The dangers and the side-effects and all that. You might think that's a little bit naive or stupid of me, but that's how my head works and that stops me from cracking. The basics, I just wanted the very basics." (P3) Study 15
Severity of the side-effects	"If I was a car engine it had just sucked all the oil out of my entire body so my knees, my shoulders ache like they've never ached before" Participant 8, age range 50–64, tamoxifen Study 1 "it was affecting my life quite badly; I mean you go out for a meal and you are sitting and the water is lashing off you, and you have only had a cold drink It's really quite debilitating at times" Participant 16, age range 50–64, tamoxifen Study 1 "Anyway immediately I noticed the hot flushes and they were terrible to start with I was sometimes getting 7 or 8 a night and just drenched and just waking up, I couldn't sleep" Participant 14, age range 50–64, tamoxifen Study 1 "I had quite a busy jobSo I stopped that so you know I really could pretty much say I'm doing hardly anything and yet I'm still exhausted all the time" Participant 18, age range 50–64, letrozole Study 1

	"We're having to downsize our house so that we can accommodate the fact, because I would rather live in a smaller house costing less money, so that I have the option that if I'm still not well enough I don't have the pressure of having to go back to work" Participant 26, agerange 50–64, tamoxifen Study 1 "Well, I felt more emotional, I suppose I felt more PMT-ish I feel I get a bit panicky, but that's, maybe, just old age, I don't know Because you can't blame things on what you're taking" Participant 1, age age ≥65, anastrozolewhich was changed after 3 months to tamoxifen followinga bone scan Study 1 "I am more forgetful I work harder at work to do the same job that I used to just do It's harder for me to stay focused, to concentrate, to think clearly, to remember everything" Study 3 "Because of the side-effects and my hands I'm an artist I'm a floral designer I couldn't I still can't pick up a straight pin I can't pick up anything small like a needle" Study 3 "I didn't expect the night sweats to be so bad I didn't expect them to interfere with my sleep" Study 3 "I wouldn't have ever thought that it would interfere so much that I don't feel like myself I don't have the energy I can't sleep I'm having trouble at work" Study 3 "There are days that all of you is in pain, all the body… A pain that you don't know what is hurting And it is so horrible … you try to be still so it doesn't hurt You can't cook, you can't clean, you can't even bathe because…the pain is in all your body" Study 4 "There are days that I feel very tired, I don't want to get out of bed, there are also days that I feel a lot of pain in my muscles, all my body hurts, very depressed, depression, I feel like crying" Study 4 "And she [a nurse] told me, she said yeah that's Tamoxifen That's one of the side-effects So I told her wow, …I never knew…Because the first time when I was on the Tamoxifen, it's like sometimes I would be in a rage" Study 4 "I was on crutches I was using a cane I couldn't get out of a chair because my knees were so bad I mean they still are, but they're 100 % better, and it's been a year and a half, and I went on a site called askapatientcom I read case histories from age 37 to 73, who had been on just Arimidex, and I was blown away at how many women have suffered this knee problems… And so… I Googled Arimidex and started to read about it… I mean I have a folder that's probably this thick about it It's nasty It's terrible stuff" Study 4 "It is an experience that led me into a deep depression, that led me down" (interview 4) Study 5 "The only thing that bothers me is forced menopause, hot flashes. . .and the loss of sexual desire... This is not a positive experience" (interview 27) Study 5 "great impact on sexual life because of vaginal dryness... I don't know how to describe it. I'm used to face and manage the situations that are hard, but it is upsetting" (interview 24) Study 5 "I don't want to be excessive but my hepatic steatosis worsened and it is altering all my liver values. I never had so high transaminases and gamma glutamyl transferases. Then there are also other effects that I do not know precisely to what are associated because I also take 'Enantone.' For example, I also have joints and bone pain, above all at the level of the sacrum that do not allow me to stay sitting for a long time; then I also gained weight,. .. awful hot flashes also at night. . .at any time!" (interview 22). Study 5 "It is disabling...the physical pain is not well accepted at all" (interview 14) Study 5 "I feel very ambivalent about this treatment at the moment I have put on 5 kg since I started, it worries me a lot Then I had a check-up with the gynaecologist which showed that tamoxifen has caused a cyst on an ovary So tamoxifen wants to stop my hormonal system from working, but the cyst has made the system want to work I found myself 10 days ago with my body really upside-down My belly looked as if I was 5 months pregnant, inflated, hard, horrible At the same time, the blood tests showed that my hormones are a little upside-down Since I started taking this medication, I have also had a pain that I did not have before in the breast, and very poor circulation in the legs I have been having a lot of hot flushes too That's horrible, it's like a wave, all the points on your body you can imagine are sweating When that happens, it is uncontrollable, and you feel terribly unclean" (W, aged 50, 9 months of treatment) Study 9 "The hot flushes, that's what made me suffer most It is the most difficult thing to cope with I know there is no solution: I am not allowed to take any of the effective ones: oestrogen I can't take, and soya products I can't take either The only thing that I am allowed to take is abufene, but it makes absolutely no difference It's the same with homeopathy" (G, aged 52, 10 months of treatment) Study 9 "One month after undergoing chemotherapy, my periods stopped And since then, things have not been back in working order The question is therefore: is it the tamoxifen which goes on stopping the periods? Or the pre-menopause, as the doctor said? I was taking hormones But as the hormones were stopped and I was given tamoxifen, the hot flushes started to occur again Was that due to stopping the hormone treatment? Was it due to tamoxifen? That is the big question I don't know I really don't know" (M, aged 49, two years of treatment) Study 9 "I put on weight, but maybe it was because I stopped smoking? As far as hot flushes are concerned, I had some before, but right now I am having more and more Every hour, suddenly I'm in a sweat! Does tamoxifen increase them? I wondered whether stopping smoking did not increase my hot flushes two-fold, as well Or going back to work In addition, the weather is so hot right now" (R, aged 46, 6 months of treatment) Study 9 "To kill off the female hormones that I produce is unacceptable to me It is an additional mutilation after the mastectomy, a loss of my female image I was born a woman and I want to remain a woman With this treatment, we have to make up our minds to take it every single day for five years Five years is a long time, and these five years

	are important when you are not far from the menopause like me, because there's no turning back We are pushed into the menopause without being able to go back It also means that we will not have access to alternative treatments for menopause So we will age more quickly" (I, aged 50, 15 months of treatment) Study 9 "See, that's what I was talking about, those sexual issues." Study 10 "Because for me, especially being young or old, I guess it doesn't matter. You worry about the body image." Study 10 "I guess I didn't expect to feel as weak." Study 10 "It makes me feel better to know that fatigue is an effect." Study 10 "You might done lost a lot of weight and you might be looking bad." Study 10 "I told them, I'm still fat as you know what. I ain't lost no weight. I still look good, just ain't no hair. I said, you don't kill no hog for no hair, baby you want the meat." Study 10 "Overall it feels like a torch... the chest area and face and forehead; my forehead's like soaking wet ... they come on real fast and last about a minute or two... during the night I might wake up it seems every two hours... like at midnight, two o'clock, four o'clock, six o'clock, and you know it wakes me up and sometimes I can't go back to sleep so that is an additional problem." Study 11 "The only thing I do have a problem with, and I have noticed it, is my memory. Now I'm remembering a lot of things... today, talking to you, but if somebody said, "Well, I told you that yesterday," or "Don't you remember I..." "I can't remember." I have to really think, and that scares me. I mean I had a bad memory before (laughs)... but it, it is worse. It is, it is worse." Study 11 "I've worked with lots of women, and we all say (laughter) estrogen, the menopausal breakdown. But, I have days when I just... can't remember things like names or specific words for thoughts... And I'm usually really good. I love words, and I'm usually pretty good with them. But, I just have days when I can't, and I'm not as articulate... I just finished helping with the summer camp and we had about 18 college counselors... I remembered all their names, and once in a while I'd completely blank... but I had a notebook, I had my cheat sheet" Study 11 "The main side-effects are stiff joints, aching muscles and indeed [in response to another participant] less sexual desire. The consequences can be annoying. I used to walk long distances with friends but I cannot do this anymore. This is also disappointing from a social point of view." Study 13 "What is important for me is to go back to my lifestyle, which is very active. And with the side-effects, I would have been on that couch." Study 14 "And I have two, three grandchildren. I love children…. So, when I see them, I want to play with them … but physically I can't do it. So, that makes me—really upsets me. I think that's the thing." Study 14 "I understand that I could take it as much as I could bear it and if it's helping me. Well, if I start getting, you know, my bones deteriorating and things like that, losing a lot of hair, where I could see physical change in me, I will know that I will stop it." Study 14 "I am unable to undertake too heavy/many physical tasks. I should perform light work only. For example, I easily feel tired when cooking. I have to take a break and lie down on the bed for 15 minutes. After boosting my energy, I get up and continue to cook." (65 years old, 53 months) Study 16 "My arm on the affected side is too weak to carry things. If I hold on to something, walk for a short distance, or do more household chores than normal, my arm becomes swollen. Now, I seldom use my arm and perform less housework." (63 years old, 18 months) Study 16 "I think they have explained too little about side-effects. They have actually minimized them, which makes them worse than I imagined them to be. Now I have to learn to deal with it after I have experienced them and this is very difficult." Study 17 "I turned into a monster over the few months following chemotherapy. I thought it was the stress of what I had been through, but it went on and on. I read on the internet that it could be the tamoxifen. I felt depressed and would swing into a temper for no reason." [P22 nonadherer] Study 19 "It [tamoxifen] altered my mind […] I felt almost suicidal with it. I didn't realise it was the drug until I got sick and didn't take it for a week. I felt so much better." [P21 nonadherer] Study 19 "And I didn't want to go out and I became quite withdrawn really, so no, it wasn't acceptable." [P20 nonadherer] Study 19 "I didn't really feel like doing anything. I carried on going to work, that was fine. I just couldn't be bothered to do anything out of work – like meet friends, see family. I just wanted to vegetate at home." [P24 nonadherer] Study 19 "I knew quite a few and people who knew women who had put on a lot of weight which they blamed on the tamoxifen […] How am I going to teach [aerobics] when I look like a balloon? […] So that was a problem and that was all part of the hysteria." [P27 nonadherer] Study 19 "I got thrown into the menopause. […] [O]ne of the things that upset me most at the time [was that] I lost all interest in sex overnight – it didn't help my husband as you can imagine." [P30 nonadherer] Study 19 "I didn't even know my body was going to go through that. It hit me like a boom." Study 20 "I already had osteoporosis to start with, and the Femara® certainly did not help." [My doctor] told me I would probably have night sweats and hot flashes, but that's all I really expected. I didn't expect the [severe side-effects] I had. … It started with pain in my shoulders, and then it moved to my jaw. Eventually, it moved to every joint in my body." Study 20

	"I just don't feel exactly like myself [on Arimidex®]. I don't feel real clear-headed, and I feel groggy a lot of the time. If you're not sleeping well, you don't know if one thing causes the other." Study 20 "I had extreme joint pain, back, knees, hands, feet. I had swollen knuckles. My ring size went up like at least two sizes. I couldn't wear my shoes. . . . It was bad." Study 20 "I had . . . what I have come to find out, as every conceivable side-effect that the drug has. . . . It started out with pain in my shoulders, and then it moved to my jaw. Eventually, it moved to every Joint In my body. Every muscle In my body hurt. You could touch me, and I would bruise, and when I would bruise, I went pale. I . . . for an example, I had a toe that rubbed in a shoe, and it got black from that, and it remained black for the entire nine months that I was on tamoxifen." Study 20 "I had such chest pain I thought I was having a heart attack." Study 20 "My fingernails became brittle. I also had some hair loss." Study 20 "Well, just generally, I had some hair loss. I had dry eye. I had vaginal dryness. The kinds of effects that losing all of your hormones does to you." Study 20 " . . . the hot flashes. I would wake up during the night and be drenched. I skipped one month [of AET]." Focus Group 3, Participant F. Study 20 My joints and the cramping were sometimes unbearable. I would cry. When it would hit me at night, I would be sound asleep and it would jolt me out of my deep sleep. In the beginning I did not know how to deal with it. It affected me in my working environment and it affected me in my free time, and my family. (AET persistent) Study 23 I started to withdraw from social situations. I didn't trust my body to co-operate. I missed out on quite a few things, because I was too afraid that [due to the diarrhea] I would have to run or, change my clothes or have a shower. And make a mess in public. Emotionally, it was devastating. (AET persistent after switching AETs) Study 23
Ability to adapt to the treatment and its side-effects	"They said that it would remove the, I can't remember the name it's something, oh dear, they did tell me what the Letrozole did and I can't remember what it removes but then if that is removed it can cause brittle bonesWhich is why I've got the other tablets, they told me that I did have brittle bones and that I could if I fell I could you know break quite a lot so they prescribed the Alendronic, they didn't tell me how bad the brittle bones were, I asked the doctor and he said no I don't have that information." Participant 22, age ≥65, letrozole. Study 1 "Felt terrible and desperate sometimes I stopped taking the medication for two weeks until my doctor referred me to a psychologist I am taking Capecitabine and anti-depression drugs now I think I need to learn to recognize abnormal symptoms" Patient 5 Study 2 "Sometimes I am not sure if it is normal, bad or very serious Sometimes I knew that it was not normal when my hands and feet were numb But I was still not sure if I should wait until the next doctor's visit (or see a doctor immediately)" Patient 3 Study 2 "When you first started to develop the side-effects, she [MD] would tell you things that you would try to do to just sort of get over, or get through, or alleviate some of them When they didn't work, then you sort of figured it out on your own" Study 3 "You can take the suppository [estrogen containing for vaginal atrophy] First thing the pharmacist says 'well I thought you weren't supposed to be taking estrogen' and I said 'well they told me I can take these" Study 3 "I'm tired of taking [pills] When someone says 'take a pill for this [symptom]', I don't want to start another pill I think about all these other side-effects The lesser of two evils" Study 3 "I just know it's very frustrating though When you have estrogen positive tumors, that everything they recommend for these sleepless hot flashes are estrogen based It's like ok well what's plan B? I can't take that so what else can I do?" Study 3 "You learn to live with it...as it could save my life" (interview 22) Study 5 "On the Internet, a patient said that you should take the pills in the middle of lunch, so I tried to do the same" Study 6 "My sisters take it at 11 am They said to me, "Take it at 11 pm," so I did it Perhaps it's better for me?" Study 6 "If we have side-effects, it is for the doctor to say what to do I'm not capable of knowing what to do" Study 6 "My gynaecologist prescribed to me zinc, potassium, calcium Perhaps I tolerate the treatment better with this I don't know if it's related, but I tolerate it better" Study 6 "I take it before going to bed because I fear nausea I said to myself, "If you have nausea, you're going to be asleep" Perhaps it's going to be better" Study 6 "The hot flashes with tamoxifen Arimidex I had joint pain but I am off of it now" FGA Study 8 "I am not having the joint pain on tamoxifen but I may not have been [illegible]on it long enough But I am having hot flashes" FGA Study 8 "They [doctors] recommended I take it [AET] in the evening so that I'm not dealing with being hot during the day. So it was more just controlling when I was going to have them because that's a common side-effect with it." Study 12 "It's an antidepressant... But, for whatever reason, that medicine does decrease hot flashes." Study 12 "My oncologist recommended to try to take over-the counter supplement first, if it does not work, then she would prescribe me something." Study 12

	"I have been very open about my breast cancer. This encouraged the people around me to also talk with me about breast cancer. I got many warm reactions. The chemotherapy made me very ill, but it went away. Starting with endocrine therapy did not pose a problem to me. I am happy that there is something that I can do to prevent metastatic cancer." Study 13 "To me, endocrine therapy was just the next step in the sequence of surgery, chemotherapy and radiation therapy. When I started using endocrine therapy, I thought I had gone through the hardest part of my treatment and I considered endocrine therapy as a protection for the years in the near future. Although, I still feel the same about that, endocrine therapy has a big influence on my life. On the positive side, I have not metastatic cancer or recurrent breast cancer. The difficult consequences of Tamoxifen and later also Arimidex were the severe depressive episodes. I could not adjust to them, whereas I had accepted many other adversities. My oncologist convinced me to continue." Study 13 "Maybe I won't take that today and see if it helps," Study 14 "I mean manage it? I don't know? That's it. Just live with it." Study 14 "[My physician] said that if [the hot flashes] were too intense, she could give me something that would sort of balance them out. And I said, 'Well, I don't want another pill.' I really don't want another pill. I take so much already, and I'm practically kept alive with chemicals as it is." Study 14 "Well, the doctor said, 'Is it intolerable? Is it unbearable? Because I can give you some pills, but there are side-effects to the pills.' …But I said, 'I'm taking so many pills already. I'd rather not. If I can manage it, if I can tolerate it." Study 14 "This is controlling one thing and you have to have your side-effects. You have to take the good with the bad, you have to accept it." (P16) Study 15 "The only thing would be the sweats, but I can live with that. It doesn't stop anything, it wouldn't stop you from living your life." (P22) Study 15 "The bone pain, I feel ninety but the frame of mind I'm in is, I am still willing to put up with them side-effects. (P14) Study 15 "It does put up weight, I swim every morning, if I don't swim I'd try go for a walk, you have to watch what you eat as well, it would bother me, but it wouldn't bother me enough to stop taking it. It is possible to lose the weight; it's just harder." (P22) Study 15 "There's days you are exhausted with it all, these sweats, just go away. I had me hard time, can that not be it. Mentally I just (pause), say it's coming on me, just deal with it, take a cold drink of water and relax then. This is gonna happen to you but it'll pass. You can't fight it, you just have to let it happen because it's just gonna come" (P16) Study 15 "You kind of get used to it and you laugh it off. If you're sitting with your friends having a cup of coffee your saying I'm going, I'm going, here we go girls (laughs), I'm like a traffic light." (P16) Study 15 "I read on the internet about looking after myself […] I eat much healthier now, and avoid alcohol and caffeine. A bit boring, but it helps. The side-effects are less now." [P7 adherer] Study 19 "I wanted to be able to do something for myself. I wanted to be able to adapt and have some way of coping with the side-effects. I started by eating more healthily. It was a way of taking back control." [P5 adherer] Study 19 "My experience with Arimidex" . . . I got through it. It was a little inconvenient having the flashes, but no big deal." Study 20 "I mentioned it to [my doctor], but I knew it was just one of those things I would have to cope with, so I just did." Study 20 "If the hot flashes are to help me stay alive, then I'll just turn down the heating system." Focus Group 3, Participant Z. Study 21
Ease of access and availability of professional support (specialized physicians, general practitioners, nurses and pharmacists)	"I would rather have somebody tell me that they don't know why I had a reaction to this or that, rather than just make me feel like I'm a child or it's just your hormones or it's just your mental incapacity" Study 3 "I cried, I lost it, and then right away, he wants me to go see the psychiatrist! I don't need a psychiatrist or psychologist" Study 3 "When you first started to develop the side-effects, she [MD] would tell you things that you would try to do to just sort of get over, or get through, or alleviate some of them When they didn't work, then you sort of figured it out on your own" Study 3 "To have these symptoms and at some point you feel like there's no one to talk to outside of other people who are going through it or have been through it" Study 3 "I feel like there isn't any help really available (symptoms)" Study 3 "What'll help is taking the load off the oncologist, because their days are so busy And when you know they're dealing with people that are sick and going through treatment and we need someone to discuss these things now (symptoms)" Study 3 "There has to be somebody helping us with those things Why am I going off of this [AET] in 5 years? We need a theory about what this Arimidex is doing to us I worked in the medical field I really don't understand It stops estrogen, ok, that's all I know I think that would really be helpful to help people understand why they're taking it (symptoms)" Study 3 "Things that would help with the side-effects rather than waiting until you see the doctor 6 months later You probably could have solved it within the first week starting therapy, or not had so much trouble with it, because nobody told me" Study 3 "The doctors, they are not listening; they are always in a hurry " Study 6 "When you manage to speak to the doctor, all they say is, "It's the side-effects! That's all!" Study 6 "[The doctor is] nice, I mean, but he does not explain a bit" Study 6

	"We have no time for questions" Study 6 "Those out patients appointments, you see a different doctor all the time and they spend more time, looking through my file trying to read up what's happened to me. They're so busy you barely get time to talk to them at all about how you're feeling. You get your treatment and then you toddle off on your merry way and you're left to deal with the rest of it on your own." (P12) Study 15 Each time I was coming back to the clinic I was seeing registrars. I didn't feel I was getting through with my questions. Some didn't know the kind of cancer that I had. There should be something personal . To recognise the person who's sitting in front of you as opposed to the, the breast cancer. Treating the cancer rather than the person, with the cancer. Which is very, that's science isn't it, the objectification. (P2) Study 15 I just feel the medical profession certainly doing their job will prescribe, prescribe, prescribe, I'm not sure they want to listen to somebody that doesn't want to go down the route of what they prescribe. (P23) Study 15 "I read the patient information leaflet and look for testimonials on the internet from women who have the same side-effects as I have. When I find an answer, I feel reassured. I regret I do not find reassurance and answers with my physician." Study 17 "When I mentioned side-effects I got the reaction: "You have to accept you are getting older." At that point I disconnected myself from the conversation; there was no longer any point in talking to this person. I was furious, but you can't do anything with that furiousness, and I didn't want to do anything with it anymore. . . At that moment you collapse and you think: "It doesn't make sense anymore to say anything". Study 17 "I would like to say to the physicians who work by appointment, to take a little more time and to listen a little better. I had the feeling that I could not be outside fast enough. I was not dressed yet and he was already writing a prescription. That hurts." Study 17 "It's not about the almighty physician, but about admitting that they do not know everything. And that physician admitted it and then you feel treated in a human way and then that's ok for me. That is all I need in order to continue, then I can be much more accepting." Study 17 "This is the one thing that I do find a lot of women struggling most with, that they feel so. . .they're just not listened to. They're not being validated in what they're experiencing." (Bonnie, 61, discontinued) Study 18 "The breast care nurses were lovely, but rushed off their feet. You didn't want to disturb them unless it was life or death, if you know what I mean. They had a lot of people to see who had far greater problems than me." [P23 nonadherer] Study 19 "They are cautious with the amount of information they give you. You can tell they are not telling you everything. I can understand why they do this, but I would have preferred more information." [P31 nonadherer] Study 19 "They answer questions but very much within their own confines. [P27 nonadherer] Study 19 "Nobody's asked me about it since And the Doctor [GP] knows that I'm on it, but we never discuss it." Participant 2, age range ≥65,letrozole Study 1 "I'm not meaning this badly, but the GPs and everything; they probably know about chemotherapy and everything, but the people at Hospital X, they are dealing with it all the time if I say something to the Doctor I might make a comment but then have to explain it a wee bit, whereas if I am in Hospital X they know exactly what I am talking about." Participant 15, age range ≤49, tamoxifen Study 1 "I get on well with him and I find him very good but I got the impression that he [GP] didn't want to be involved in the cancer issue, he said something to the effect of 'oh that was for the hospital to deal with but how are you in regard to your other medication' and this sort of thing, it was as if that's a completely separate thing that the hospital will deal with" Participant 18, age range 50–64, letrozole Study 1 "The relationship isn't there I wouldn't have thought about going to see the pharmacist to talk about my side-effects with any medications, I go to the GP about that" Participant 20, age range not known, tamoxifen Study 1 "I don't have a partner. I do have family and friends. As long as people are not familiar with cancer, they do not know very much about cancer treatments. To us, the difference between chemotherapy and radiation therapy is quite clear, but I often notice that in explaining this difference I am telling someone something new. Endocrine therapy is absolutely vague for the people around me. My general practitioner never asks about my surgery, chemotherapy, radiation and endocrine therapy. I am quite on my own." Study 13 "Just before I started using endocrine therapy, I got a brochure and I read it carefully. I don't think I discussed the information of the brochure with my oncologist. I spoke with him later when I was already using it and experienced side-effects. I have a need to gain knowledge you know. When I am concerned about something, I'll try to find information about my concerns and if at that point I do not understand the information I ask my oncologist or primary care physician. However, my primary care physician often needs to consult my oncologist, so that does not work out very well." Study 13 "Yesterday the script ran out and they sent me five from the chemist 'til I get the prescription from the doctor. They would feel that I should know when my prescription is due. I like to see as little of doctors as possible and I nearly have to pluck up the courage to ring the GP to say, oh I need the prescription. I hate it, it's another little thing you've to think of and remember and do." (P7) Study 15 "I had a long conversation with him [GP] about it – he really cared. He swapped me on to this one – I know he is doing what he can. If you feel someone cares, it kind of encourages you to keep going, if you know what I mean." [P18 adherer] Study 19

	"You have the hospital that dealt with the issue and then after you have come out of hospital it's the GP but the GP just refers you back to the hospital. So you have that triangle […]they forget to look at you as a whole person […] They are only interested in their own department." [P25 nonadherer] Study 19 "Don't get me wrong. My GP is lovely. But they don't know much about treatments for breast cancer. I'd rather talk to someone at the hospital." [P22 nonadherer] Study 19 "Yes, they've got a little consultation room that you can go in privately and talk to them [Pharmacist] and, you know, I think these women are very smart and they know their drugs" Participant 13, age range ≥65, anastrozole Study 1 "Yes I mean I wouldn't have a problem with that, either that or the doctor you know I would chat to the doctor but yes I would go to the chemist if I had any problems with the prescriptions or the tablets" Participant 22, age range ≥65, letrozole Study 1 "With the hot flushes the Pharmacist did suggest instead of taking it in the morning, to try taking it at night to see if it made any difference But I found it made the flushes, if anything, worse at night So I went back to taking it in the morning" Participant 16, age range 50–64,tamoxifen Study 1 "The relationship isn't thereI wouldn't have thought about going to see the pharmacist to talk about my side-effects with any medications, I go to the GP about that" Participant 20, age range not known, tamoxifen Study 1 "No I wouldn't have thought of the pharmacist as a place to go about this I mean I would you know I would ask the pharmacist what cough medicine to buy or something like that" Participant 23, age range 50–64, letrozole Study 1 "They're [pharmacists] not interested, all they're interested when you do your repeat prescriptions are your quantities" Participant 3, agerange 50–64, letrozole Study 1 "You can take the suppository [estrogen containing for vaginal atrophy] First thing the pharmacist says 'well I thought you weren't supposed to be taking estrogen' and I said 'well they told me I can take these" Study 3 "Do you get a chance to ask the pharmacist?" "No because I just think they are just handing me the medicine and nobody explains" "Well, sometimes you need to ask" FGA Study 8 "I was at Rite Aid and I went to Walgreen's because they could get the medicine faster and then they kept giving me the run around I guess they didn't know what to do I went back t Rite Aid because I didn't have to deal with so many pharmacists" FGB Study 8 "When I get a new prescription, I am able to sit down with my pharmacist and he will explain what it is and how to take it and ask questions and make sure I understand how to take it" FGA Study 8 "I go to Ike's and they are very nice They explain to you, they ask you "do you understand the medication?" You can tell them no or you can tell them you and if you don't they can explain it to you" FGB Study 8 "I don't have a lot of difficulty if it is typewritten and where you can read it on the label I like the little strips on the bottle They make it easier to understand" FGA Study 8 "There is far more information than I need All I want to know is a few simple things— am I going to get nauseated? Am I going to be able to drive?" FGA Study 8 "Most of us are used to taking the bottles and reading the labels Most of us are just take charge persons because most of us take care of families" FGA Study 8 "I talk to my pharmacist because I have so many doctors My pharmacist knows more about me He knows all my medicine" FGB Study 8 "I stay at Walgreen's They know me real good I call my medicine in and they call me and tell me my medicine is ready and I go down and pick it up" FGB Study 8 "It [transition to primary care] was annoying because you know that means you're really getting nothing. No follow up. Because you don't get any follow up from a GP [family physician]. They say they don't know anything about cancer, it's too complicated." (AET non-persistent) Study 23 "The medical system is so overloaded and to deal with your GP [family physician] is difficult. They don't give you much time. You wait two hours to see him [GP], and you get to talk to him for about two minutes. You have to talk kind of fast, and you never get what you wanted to say all out, because you have about two or three minutes. It's not that conducive to getting a whole lot of help." (AET non-persistent) Study 23 "I wanted to be followed up. If they're going to start fiddling with your hormone levels, they should be checking you every three months. There's no checks and balances. If I had felt I was being followed and people knew what was happening to me, I would have felt much better. I felt totally alone." (AET nonpersistent) Study 23
The relationship with healthcare providers	"For me establishing personal relationship with the oncologist was so important" (interview 18) Study 5 "You should customize the relational approach to patient" (interview 3). Study 5 "He (doctor) told me that I'd have to take it, and so I took it." Study 11 "he was nice" Study 12 "he's very positive but he's realistic" Study 12 "the doctor was very present and caring" Study 12 "very respectful and not condescending" Study 12 "He [oncologist] knew me by my name, my face. When I came in, it was like they treated you like you were a person and not just cattle coming through^. "He used to call me his most delicate patient." Study 12 "very well respected and prominent in the field" Study 12

	"does a lot of research with tests" Study 12 "respectable person" Study 12 "Why am I continuing with it? I think a lot of it has to do with kind of the confidence in my doctor…she is the doctor and she knows what the clinical trials are showing." Study 12 To me, endocrine therapy was just the next step in the sequence of surgery, chemotherapy and radiation therapy. When I started using endocrine therapy, I thought I had gone through the hardest part of my treatment and I considered endocrine therapy as a protection for the years in the near future. Although, I still feel the same about that, endocrine therapy has a big influence on my life. On the positive side, I have not metastatic cancer or recurrent breast cancer. The difficult consequences of Tamoxifen and later also Arimidex were the severe depressive episodes. I could not adjust to them, whereas I had accepted many other adversities. My oncologist convinced me to continue. Study 13 I had a long conversation with him [GP] about it – he really cared. He swapped me on to this one – I know he is doing what he can. If you feel someone cares, it kind of encourages you to keep going, if you know what I mean. [P18 adherer] Study 19 "I would have preferred to see always the same oncologist, I had difficulties because when doctors changed I found myself thinking I had to start again, to find problems, misunderstandings..." (interview 10) Study 5 "Those out patients appointments, you see a different doctor all the time and they spend more time, looking through my file trying to read up what's happened to me. They're so busy you barely get time to talk to them at all about how you're feeling. You get your treatment and then you toddle off on your merry way and you're left to deal with the rest of it on your own." (P12) Study 15 "Each time I was coming back to the clinic I was seeing registrars. I didn't feel I was getting through with my questions. Some didn't know the kind of cancer that I had. There should be something personal . To recognise the person who's sitting in front of you as opposed to the, the breast cancer. Treating the cancer rather than the person, with the cancer. Which is very, that's science isn't it, the objectification." (P2) Study 15 "I wouldn't go to the GP [family physician] because I don't feel that they're up on it [AET]. Well, I don't feel mine is up on all that. They don't have that knowledge. I think someone dealing with cancer, in the cancer setting, has more details on symptoms from one of those drugs." (AET persistent) Study 23 "He [oncologist] said you wouldn't complain if you were on chemotherapy, given intravenously. You wouldn't complain about the side-effects. And I said, 'No.' And he said, 'Well, look at it this way. You are taking a little bit of a chemo every day, and so you just have to learn to deal with it." (AET persistent) Study 23
Support from family, friends, co-workers and other patients	"Well your friends and relatives don't want to hear about it [symptoms]" Study 3 "You really can only go so far with, even your husband They only want to hear what's going on for a couple of minutes (symptoms)" Study 3 "In case I forget, my husband reminds me" (interview 7) Study 5 "I have friends, but [they are] friends who don't understand a thing about endocrine therapy For one of them, my treatment goes right over her head; she can't understand I'm tired It's upsetting, so I don't talk about it anymore Even my mother doesn't understand" Study 6 "My mom... would push me to take it and say 'you need to continue on this." Study 11 "... I don't think he [husband] thinks about me taking my medication at all." About it being a solitary experience" Study 11 "I don't have a partner. I do have family and friends. As long as people are not familiar with cancer, they do not know very much about cancer treatments. To us, the difference between chemotherapy and radiation therapy is quite clear, but I often notice that in explaining this difference I am telling someone something new. Endocrine therapy is absolutely vague for the people around me. My general practitioner never asks about my surgery, chemotherapy, radiation and endocrine therapy. I am quite on my own." Study 13 "I'm probably not the most organised person and I don't know why, I know it's coming up to it because the pack is going down, and my husband goes mad because he'd say that's so important and you're just leaving it like that and then I'd get to the last one and I'd realise it's Saturday and they're not open on Sunday." (P17) Study 15 "We limit our sexual life because I am a (cancer) patient. If I feel physically fine, we occasionally satisfy our sexual needs. However, we usually do it at longer intervals, unlike what normal people do." (57 years old, 54 months) Study 16 "Although I seldom do household chores nowadays, I feel that the burden on my family may be lessened if I can take good care of myself." (57 years old, 54 months) Study 16 "In the beginning, it was very difficult for me that my husband had to clean the house and I could only look on. I sat there crying because I like to clean the house and I could do nothing." Study 17 "For him, I regret. I do not feel the desire to have sex anymore. That is over. And then I think: "He is normal". I do not feel normal anymore. I do not feel like a woman anymore." Study 17 "You always have the same complaints and you always have to repeat them, but you can't do this at home. When you always repeat the same complaints to your husband like: "I have got this again, or that again", after a while they say: "Can you ever stop complaining?" or "God, you are a selfish person." The children would say: "You always have to complain and whine.". I really don't do that anymore, I do not talk about it anymore." Study 17

	"He [husband] is brilliant. He's very understanding – he has been with me 100% through everything. He has gone to hospital appointments with me but he just worries about how I feel." [P6 adherer] Study 19 "I really didn't want to take it [because of weight gain] and I have to say the only reason I have taken it, I think, it's because of my husband. Because e lost his first wife to breast cancer and I think I would be really selfish if I didn't take it for him but if it had been me I might not have taken it." [P6 adherer] Study 19 "I got thrown into the menopause. […] [O]ne of the things that upset me most at the time [was that] I lost all interest in sex overnight – it didn't help my husband as you can imagine." [P30 nonadherer] Study 19 "I don't talk because I'm not able to talk about it." With relatives for support" Individual Interview, Participant C. Study 21 "...the discomfort of having to take it in front of other people who can ask: 'How long do you have to take it for?' or 'lt is a small chemo?" (interview 12) Study 5 "People say oh you're so positive, of course I was positive because the alternative is having a chat with the undertaker. And I suppose on the tamoxifen I feel I'm avoiding that. I think l if I was off the tamoxifen I could be cognitively quicker, I could lose the weight and I would be probably amazed at how better I'd be if I was two or three stone lighter but I would be afraid to take that risk." (P7). Study 15 Everyone seems to think that, in the end, I've gotten off rather easy: "You've only got one pill left to take, no more chemotherapy, no more radiotherapy. The worst is behind you." It's all minimized. They consider me to have had only half, or even quarter of a cancer. I have some issues with this. I did have the side-effects of the AHT. I felt impaired in my femininity. The fact that people then minimized it all, that was the most difficult to deal with. Study 17 I talk to my Friends but not for very long and not in any detail partly because I don't want [them] to think 'I'm not going to bother seeing [name of participant] you know.' – They are only going to go – 'oh she's depressed or something '. [P31 anonadherer] Sudy 19 "Only patients with similar experience can understand me I have encountered difficulties I really want to know how others deal with the difficulties" Patient 6 Study 2 "The successful experience of others helps us to adapt to the disease and life changes Once I have decided to give up the treatment All the doctors couldn't stop me But one patient with similar experience pulled me back I know I am not the only person suffering (from the disease and treatment)" Patient 9 Study 2 "Any type of communication with other patients such as group events, web-based networking, and We Chat group are great We have the same experiences and emotions" Patient 7 Study 2 "To have these symptoms and at some point you feel like there's no one to talk to outside of other people who are going through it or have been through it" Study 3 "I went to a really good (support centre). It is lovely for people who are in a time in their life, when it is like the rug has been taken from underneath you. I feel that if you go to the things that are in place to help you, then you have a better chance of coming along the road and coming out the other end and thinking yeah, I'm good now. (P11)" Study 5 "Do they realize how hard it is to support this treatment? I don't think so" Study 6 "Suffering from cancer is unfortunate, but I am fortunate to meet new friends here. When one of us has small things to celebrate, we usually chat or gather together. We quickly forget our negative thoughts." (65 year old, 53 months) Study 16 "We were twelve and twice a day, morning group and evening [discussion] group, I received all the information from them because they had gone through it before me." Focus Group 5, Participant S. Study 21 "I want my life to be about other things. So, if people ask me how are you doing, I'm not shutting them out, but I don't want to bring them into the full depth of it. I've been awake since three o'clock this morning 'cause I woke up soaking wet and I'm grumpy and I don't want to bring that to my friends and family all the time. So, I don't talk about it as much with them. My husband knows. But I also don't want our marriage to be just about that." (AET non-persistent) Study 23 "I can see some ward mates are very upset, so I would share my experience with them and tell them how I overcome difficulties and build up confidence."(P15) study 24 My husband divorced me. We got divorced after surgery and chemotherapy. (With tears in her eyes) he may be afraid of my looks after chemotherapy, and I don't want to take care of myself any more (more tears appear, which she wipes off). (P30) study 24
Owing it to everyone involved	"I really didn't want to take it [because of weight gain] and I have to say the only reason I have taken it, I think, it's because of my husband. Because e lost his first wife to breast cancer and I think I would be really selfish if I didn't take it for him but if it had been me I might not have taken it." [P6 adherer] Study 19 " . . . All the effort made by everyone around us to support us. What's taking a pill? We owe them that." Focus Group 1, Participant C. Study 21 "My husband and two children are a motivation for me to live." Study 24
The perception of the treatment (positive or negative)	"It's painless, I don't have any side-effects It's been very easy I consider myself really lucky But if it's working, then I've got off easy" Participant 13, age ≥65,anastrozole Study 1 "I'm living the therapy peacefully, one manages it with serenity. I live everything with great naturalness and serenity and I can manage everything very well" (interview 3) Study 5 "If I think back to what I experienced in the past with other treatments, this really is not anything major" (interview 6) Study 5 "Taking this medicine does not significantly change anything in my life,... it does not create distress" (interview 3) Study 5

Continue feeling as a cancer patient throughout the treatment, even though being told that they are cured, and cancer is completely gone.	"I still feel like I have the disease, even though it has been a year since surgery and 6 months since the start of hormone therapy. While I feel so lucky knowing that everything went well, the presence of the disease still lingers on. . ." (interview 15) Study 5 "I have lost the ignorance of childhood. When I become aware of a bodily sensation, I always think it is cancer. The least thing I become aware of, I think it's a tumor." Study 17 "Everyone acts like the treatment is over. It does not feel like the treatment is over. As long as I have to take this medication, I am not like before." Study 17 "I know I have no other choice than taking the AHT medication. It protects me against cancer and we can be reasonably sure that there will be no relapse if I take this medication for five years. I have to continue now because there is always a little voice that says: "You have had cancer"." Study 17 "I absolutely hate taking this tablet. It's a very powerful drug. It's not just the side-effects. It's a reminder of what I had." (Lauren, 62, adherent) Study 18 "I find it very difficult to be honest. . .I think the thing is anything that you find that you feel that is not right in your body then you start thinking 'I wonder if it's something serious'." (Arlene, 62, adherent) Study 18 "That would be my biggest fear is, it's not, I suppose if it's going to come back it's possibly when, but I can't live my life like that. So I kind of like have to block it and just continue as much as I can." (Elisabeth, 37, adherent) Study 18 "Someone said to me it's like having a sword dangling above your head, and it is. You just feel like tomorrow you don't know what's going to happen. It's always there in the back of your mind." (Kate, 52, non-adherent) Study 18 "It's like a trace of what we've experienced, like a passport that you always have on you." Focus Group 4, Participant M. Study 21 I do not like to stay at home doing nothing. I feel good when going to work. As soon as I am in my office and see my colleagues, I don't feel different from them and, I feel that I am in a better condition.(P6) study 24
Ability to always remember to fill the prescription and take the medication as prescribed	"Got the routine, I take the dog out, come back, have all the, have a wee drop breakfast and have the rest of the pills " Participant 22, agerange 50–64, letrozole Study 1 "I was away to New York before Christmas time, well, in November So, I had toI was trying to, I was taking itthrough the night Because I wanted to keep it in the 24 hour clock So, it wasI think it was four o'clock in the morning" Participant 5, age range 50–64,tamoxifen Study 1 "If I'm day shift I am taking them at seven, if I am night shift, I'm taking them at 8 in the morning So I am keeping them as near as possible to the twenty four hour period" Participant 16, age range 50–64, tamoxifen Study 1 "In the morning my routine is I'm going to go to the kitchen, I'm going to get my coffee ready, I'm going to get out the pills and then I'm going to drink them with water and then I'm going to have my breakfast and my coffee" Study 4 "I have learned to keep it near the cup of coffee...I remind myself by keeping it in view then, as soon I have taken it I put it away to avoid taking it twice" (interview 26) Study 5 "I tell myself that instead of the pill I am taking tamoxifen It's a hormonal treatment, and it is one pill a day I take it in the same way as I took my pill in the evening, before I go to sleep I usually put it on my bedside table, so I will not forget to take it" (I, aged 36, two years of treatment) Study 9 "About never forgetting the medication "Cause I take it with my morning vitamin, my calcium, and fish oil." Study 11 "Every morning when I get up, before I do anything else, I take my tablet out and I put it there and get my breakfast ready and then while I'm having my breakfast I take it." (P11) Study 15 "I leave it beside my prunes in the morning. And I take prunes every morning so I leave it up in the press beside the prunes." (P20) Study 15 "I haven't missed any because I have a little box with Monday, Tuesday, Wednesday, Thursday on it and I take it every night at the same time, in around the same time every night and I'd know if I've missed it." (P22) Study 15 "You get yourself into a routine and I have a routine, I take it first thing in the morning, I have me juice and me tamoxifen and that is the start of the day. And you would nearly miss it now, if you didn't take it." (P1) Study 15 "Tablets are part of your life, you won't forget. It's part of your routine, whatever I do, wherever I go, the first thing you get up in the morning, in your head, you get in the routine that it's very hard to forget." (P5) Study 15 "I go out to the kitchen every night before I go to bed and take it with a drop of water. It's the last thing I do, more or less, brush the teeth and everything else. I value it, I actually do value it. I think when something is important enough to you, you do it, like brushing your teeth at night." (P30) Study 15 "I was taking the Tamoxifen in the morning, or if I didn't take it in the morning I would remember it by twelve o'clock, if I forgot it at least I'd remember it by dinner time. Then I was forgetting to take them. I did use my alarm and then you'd turn it off and say I'm taking it now, and you still wouldn't go to take it, like if you were doing other things." (P17) Study 15 "In general it's breakfast time and I'm on my way out to school or at the very latest I would take it is 8 pm. I will not take it after 8 pm because I have to take it early again the following day. I'd be terrified to take the two together so I just leave it." (P3) Study 15 "I usually take it, after breakfast, in the mornings if I remember but if not any time during the day. If I was at home, I would definitely go and take it when I remember or if I was outside or out in work, I would make a mental note to take it, when I got home. At the start, I would keep forgetting, it happened maybe a few times a week, but now I've got better. I never took medications really, unless the usual thing, like the flu, antibiotics. This is the longest I've been on medication." (P10) Study 15

	“On Sunday because I'm going to church for communion and I don’t have my breakfast or coffee I forget. And I come back after church and I forget.” (P4) Study 15 “If you had visitors or if your routine changed or if there was something going on, I might turn round and oh God I didn’t take any of my tablets.” (P7) Study 15 “If there’s something big on or I have to bring the young one to university and then by three o’clock I could remember to take it or I might not remember to take it. But I’ll have to leave it to the following day. It would go out of my head to take it.” (P3) Study 15 “I asked myself what do I do everyday of my life? At breakfast, my jar of peanut butter . . . Every morning, it is there.” Focus Group 3, Participant F. Study 21
Changes in the patient’s usual routine	“Got the routine, I take the dog out, come back, have all the, have a wee drop breakfast and have the rest of the pills “ Participant 22, agerange 50–64, letrozole Study 1 “I was away to New York before Christmas time, well, in November So, I had toI was trying to, I was taking itthrough the night Because I wanted to keep it in the 24 hour clock So, it wasI think it was four o’clock in the morning” Participant 5, age range 50–64,tamoxifen Study 1 “If I’m day shift I am taking them at seven, if I am night shift, I’m taking them at 8 in the morning So I am keeping them as near as possible to the twenty four hour period” Participant 16, age range 50–64, tamoxifen Study 1 “In the morning my routine is I’m going to go to the kitchen, I’m going to get my coffee ready, I’m going to get out the pills and then I’m going to drink them with water and then I’m going to have my breakfast and my coffee” Study 4 ”I have learned to keep it near the cup of coffee...I remind myself by keeping it in view then, as soon I have taken it I put it away to avoid taking it twice” (interview 26) Study 5 “I tell myself that instead of the pill I am taking tamoxifen It’s a hormonal treatment, and it is one pill a day I take it in the same way as I took my pill in the evening, before I go to sleep I usually put it on my bedside table, so I will not forget to take it” (I, aged 36, two years of treatment) Study 9 “About never forgetting the medication “Cause I take it with my morning vitamin, my calcium, and fish oil.” Study 11 “Every morning when I get up, before I do anything else, I take my tablet out and I put it there and get my breakfast ready and then while I’m having my breakfast I take it.” (P11) Study 15 “I leave it beside my prunes in the morning. And I take prunes every morning so I leave it up in the press beside the prunes.” (P20) Study 15 “I haven’t missed any because I have a little box with Monday, Tuesday, Wednesday, Thursday on it and I take it every night at the same time, in around the same time every night and I’d know if I’ve missed it.” (P22) Study 15 “You get yourself into a routine and I have a routine, I take it first thing in the morning, I have me juice and me tamoxifen and that is the start of the day. And you would nearly miss it now, if you didn’t take it.” (P1) Study 15 “Tablets are part of your life, you won’t forget. It’s part of your routine, whatever I do, wherever I go, the first thing you get up in the morning, in your head, you get in the routine that it’s very hard to forget.” (P5) Study 15 “I go out to the kitchen every night before I go to bed and take it with a drop of water. It’s the last thing I do, more or less, brush the teeth and everything else. I value it, I actually do value it. I think when something is important enough to you, you do it, like brushing your teeth at night.” (P30) Study 15 “I was taking the Tamoxifen in the morning, or if I didn’t take it in the morning I would remember it by twelve o’clock, if I forgot it at least I’d remember it by dinner time. Then I was forgetting to take them. I did use my alarm and then you’d turn it off and say I’m taking it now, and you still wouldn’t go to take it, like if you were doing other things.” (P17) Study 15 “In general it’s breakfast time and I'm on my way out to school or at the very latest I would take it is 8 pm. I will not take it after 8 pm because I have to take it early again the following day. I’d be terrified to take the two together so I just leave it.” (P3) Study 15 “I usually take it, after breakfast, in the mornings if I remember but if not any time during the day. If I was at home, I would definitely go and take it when I remember or if I was outside or out in work, I would make a mental note to take it, when I got home. At the start, I would keep forgetting, it happened maybe a few times a week, but now I’ve got better. I never took medications really, unless the usual thing, like the flu, antibiotics. This is the longest I’ve been on medication.” (P10) Study 15 “On Sunday because I'm going to church for communion and I don’t have my breakfast or coffee I forget. And I come back after church and I forget.” (P4) Study 15 “If you had visitors or if your routine changed or if there was something going on, I might turn round and oh God I didn’t take any of my tablets.” (P7) Study 15 “If there’s something big on or I have to bring the young one to university and then by three o’clock I could remember to take it or I might not remember to take it. But I’ll have to leave it to the following day. It would go out of my head to take it.” (P3) Study 15 “I asked myself what do I do everyday of my life? At breakfast, my jar of peanut butter . . . Every morning, it is there.” Focus Group 3, Participant F. Study 21
Expense of the medications (insurance issues)	“[name of cancer center] again helped me get the medication that I needed because I could never, I think Arimidex was like 300 and some dollars… [name of cancer center] came in and they worked with the pharmaceutical house to get me the medication So that was wonderful” Study 4 “The medication is not cheap, it is expensive” Study 4 “My oncologist wrote me a prescription once for a nausea medication that cost twelve hundred dollars for twenty pills Nobody would pay for it” FGB Study 8 “I been turned down twice on blood pressure pills So in August I have to go to the doctor and get some samples of the blood pressure pills cause the insurance won’t override” FGA Study 8

	"I have had a hard time on some of my medication The insurance don't want to pay for it The clinic won't override it and they won't give it to me If I can pay for it I pay for it" FGA Study 8 "They'll look at you when you walk and they say "that'll be 140 dollars and something cents" and you say "I don't have that kind of money" You either pay or you walk out the store" FGB Study 8 "Some of the drugs are not covered by Medicare My oncologist wrote me a prescription once for a nausea medication that cost twelve hundred dollars for twenty pills" FGB Study 8 "If you can't tolerate the generic they will give you the brand" FGA Study 8 "What I do is go back to my doctor and ask if there is something else in another name that is the same medication" FGB Study 8 "I have been a survivor for three years. My regular check-up has been changed to once a year. In each follow-up, I undergo a CT scan, colour ultrasound of the breast, and pelvic ultrasound for the corpus. These examinations are expensive. However, you must attend regular check-ups if you suffer from cancer; otherwise, you may miss the early detection of a recurrence." (54 years old, 45 months) Study 16
Actions/interactions	
Looking for appropriate support from specialized physicians, general practitioners, nurses, pharmacists, support groups, family and friends	"I really appreciate my doctor I've asked her many times how long I could live She always told me (I have) a long life to live" Patient 3 Study 2 "Whenever I asked her if she can cure me, I actually just wanted a hope rather than an unreasonable demand" Patient 7 Study 2 "Even 5-minute conversation (with the doctor) can encourage me A good doctor should give us hope" Patient 1 Study 2 "I really needed understanding, kindness. . .I know that may be it is asking too much but we are not only 'physical' beings..." (interview 4) Study 5 "Even for example being contacted by telephone, email, been given support outside medical visits. . ." (interview 7) Study 5 "I would say more humanization...and then perhaps more psychological support." (interview 26) Study 5 "I would have preferred to see always the same oncologist, I had difficulties because when doctors changed I found myself thinking I had to start again, to find problems, misunderstandings..." (interview 10) Study 5 "I would have liked to be assisted not only from a medical point of view but also from perspectives such as diet" (interview 11) Study 5 "It is very important to have a support network" (interview 12) Study 5 "The goal is to heal, or to have a better quality of life, people does their best, but one needs to start by helping herself" (interview 9) Study 5 "It really helpful if you have someone that can support you and give you literature, give you researches and put you in touch with somebody else that have gone through." Study 10 "You need to go and have check-ups." Study 10 "My mom... would push me to take it and say 'you need to continue on this." Study 11 "I ring the doctor, I ring friends, I ring other people to find out. I went back to the hospital and they told me to start taking primrose oil. I'm still on it. Now it's more manageable. I cope better." (P5) Study 15 "I went to a really good (support centre). It is lovely for people who are in a time in their life, when it is like the rug has been taken from underneath you. I feel that if you go to the things that are in place to help you, then you have a better chance of coming along the road and coming out the other end and thinking yeah, I'm good now." (P11) Study 15 "Suffering from cancer is unfortunate, but I am fortunate to meet new friends here. When one of us has small things to celebrate, we usually chat or gather together. We quickly forget our negative thoughts." (65 year old, 53 months) Study 16 "My neighbors are very kind and comforting. They always ask me to go outside, and they chat with me." (62 years old, 46 months) Study 16 My husband divorced me. We got divorced after surgery and chemotherapy. (With tears in her eyes) he may be afraid of my looks after chemotherapy, and I don't want to take care of myself any more (more tears appear, which she wipes off). (P30) study 24
Looking for other sources of information	"I spend hours and hours researching (symptoms)" Study 3 "I was on crutches I was using a cane I couldn't get out of a chair because my knees were so bad I mean they still are, but they're 100 % better, and it's been a year and a half, and I went on a site called askapatientcom I read case histories from age 37 to 73, who had been on just Arimidex, and I was blown away at how many women have suffered this knee problems… And so… I Googled Arimidex and started to read about it… I mean I have a folder that's probably this thick about it It's nasty It's terrible stuff" Study 4 "Just before I started using endocrine therapy, I got a brochure and I read it carefully. I don't think I discussed the information of the brochure with my oncologist. I spoke with him later when I was already using it and experienced side-effects. I have a need to gain knowledge you know. When I am concerned about something, I'll try to find information about my concerns and if at that point I do not understand the information I ask my oncologist or primary care physician. However, my primary care physician often needs to consult my oncologist, so that does not work out very well." Study 13 "I read the patient information leaflet and look for testimonials on the internet from women who have the same side-effects as I have. When I find an answer, I feel reassured. I regret I do not find reassurance and answers with my physician." Study 17

	"I read on the internet about looking after myself […] I eat much healthier now, and avoid alcohol and caffeine. A bit boring, but it helps. The side-effects are less now." [P7 adherer] Study 19 "The online forum had other women chatting about it […] the 'chill' pillows are great at night – I bought it online." [P1 adherer] Study 19 "I turned into a monster over the few months following chemotherapy. I thought it was the stress of what I had been through, but it went on and on. I read on the internet that it could be the tamoxifen. I felt depressed and would swing into a temper for no reason." [P22 nonadherer] Study 19 "We were twelve and twice a day, morning group and evening [discussion] group, I received all the information from them because they had gone through it before me." Focus Group 5, Participant S. Study 21 "I really appreciate my doctor I've asked her many times how long I could live She always told me (I have) a long life to live" Patient 3 Study 2 "Whenever I asked her if she can cure me, I actually just wanted a hope rather than an unreasonable demand" Patient 7 Study 2 "Even 5-minute conversation (with the doctor) can encourage me A good doctor should give us hope" Patient 1 Study 2
Trying to manage the side-effects	"They said that it would remove the, I can't remember the name it's something, oh dear, they did tell me what the Letrozole did and I can't remember what it removes but then if that is removed it can cause brittle bonesWhich is why I've got the other tablets, they told me that I did have brittle bones and that I could if I fell I could you know break quite a lot so they prescribed the Alendronic, they didn't tell me how bad the brittle bones were, I asked the doctor and he said no I don't have that information" Participant 22, age ≥65, letrozole Study 1 "I felt terrible and desperate sometimes I stopped taking the medication for two weeks until my doctor referred me to a psychologist I am taking Capecitabine and anti-depression drugs now I think I need to learn to recognize abnormal symptoms" Patient 5 Study 2 "When you first started to develop the side-effects, she [MD] would tell you things that you would try to do to just sort of get over, or get through, or alleviate some of them When they didn't work, then you sort of figured it out on your own" Study 3 "You can take the suppository [estrogen containing for vaginal atrophy] First thing the pharmacist says 'well I thought you weren't supposed to be taking estrogen' and I said 'well they told me I can take these" Study 3 "On the Internet, a patient said that you should take the pills in the middle of lunch, so I tried to do the same" Study 6 "My sisters take it at 11 am They said to me, "Take it at 11 pm," so I did it Perhaps it's better for me?" Study 6 "My gynaecologist prescribed to me zinc, potassium, calcium Perhaps I tolerate the treatment better with this I don't know if it's related, but I tolerate it better" Study 6 "I take it before going to bed because I fear nausea I said to myself, "If you have nausea, you're going to be asleep" Perhaps it's going to be better" Study 6
Experimenting with alternative medicine	"I go to a homeopathic specialist who gives me trace elements to reduce the side-effects" Study 6 "Your immune functioning would be reduced if you didn't take (traditional Chinese medicine) TCM. TCM is mainly used to promote qi in your body, but adequate time is necessary to produce positive effects." (49 years old, 33 months) Study 16 "My friends suggested me to take herbal medicine after illness. My doctor also recommended the use of herbal medicine. However, I felt nauseated after taking it. My body could not tolerate it." (51 years old, 17 months) Study 16
Discuss the possibility of changing the hormone therapy medication	"Well, I wouldn't forget my anastrozole, that's for sure, it's like my best friend" Participant 11, age range ≥ 65, taking tamoxifen which was changed to anastrozole Study 1 "No one's ever asked if I'm still taking it" , "Well, I felt more emotional, I suppose I felt more PMT-ish I feel I get a bit panicky, but that's, maybe, just old age, I don't know Because you can't blame things on what you're taking" Participant 1, age age ≥65, anastrozolewhich was changed after 3 months to tamoxifen following a bone scan Study 1 "I was trying to keep it going till I got to the clinic but because I felt I couldn't drive my car I stopped it because it was only about ten days before my clinic appointment But you know I mean I knew that really ten days off it wasn't going to make any difference you know in the long term, so then I got tamoxifen and I'm fine with that" Participant 24, age range ≥65, letrozole then changed to tamoxifen Study 1 "I just decided to stay with the Arimidex so that I don't have to go through another 3 to 6 months of getting used to the new side-effects, if there were any. And apparently each of the inhibitors has side-effects." Study 14
Lifestyle modifications to adapt to the treatment and its side-effects	"I had quite a busy job So I stopped that so you know I really could pretty much say I'm doing hardly anything and yet I'm still exhausted all the time" Participant 18, age range 50–64, letrozole Study 1 "We're having to downsize our house so that we can accommodate the fact, because I would rather live in a smaller house costing less money, so that I have the option that if I'm still not well enough I don't have the pressure of having to go back to work" Participant 26, agerange 50–64, tamoxifen Study 1 "The main side-effects are stiff joints, aching muscles and indeed [in response to another participant] less sexual desire. The consequences can be annoying. I used to walk long distances with friends but I cannot do this anymore. This is also disappointing from a social point of view." Study 13 "(…) I am pretty healthy. Ok, I cannot do everything that I used to do in the past, but that doesn't make you less healthy than someone else. The advantage of everything that happened to me is that I pay more attention to myself. I rest more often, try to live in a more relaxed way, take more time for myself and set my boundaries. That's living healthy in my opinion." Study 13

	"And I have two, three grandchildren. I love children…. So, when I see them, I want to play with them … but physically I can't do it. So, that makes me—really upsets me. I think that's the thing." Study 14 "It does put up weight, I swim every morning, if I don't swim I'd try go for a walk, you have to watch what you eat as well, it would bother me, but it wouldn't bother me enough to stop taking it. It is possible to lose the weight; it's just harder." (P22) Study 15 "Puck yourself up, go out for a cup of coffee and if I got the table at the window and the tide was in and the winter sun coming, there is nothing as nice. That was my therapy and I made it my own." (P16) Study 15 "Some stimulating foods, such as chicken and beef, should be completely avoided. You cannot eat even if it's only one piece because such foods may induce recurrence." (51 years old, 32 months since diagnosis) Study 16 "Some people told me that shrimp was a stimulating food, which was harmful to health, but I don't think so. I was told by a dietician that shrimp contains high protein levels, and we should eat it." (54 years old, 45 months) Study 16 My arm on the affected side is too weak to carry things. If I hold on to something, walk for a short distance, or do more household chores than normal, my arm becomes swollen. Now, I seldom use my arm and perform less housework. (63 years old, 18 months) Study 16 "We have not felt normal since we suffered from this illness (cancer). What can we do for survival? We have been mentally exhausted. We can't live without medicine. We need regular exercise. We can't go outing because we need to take herbal medicine twice a day. We can't also eat outside because foods are unsafe and unhealthy. We have no choice if we get this illness." (49 years old, 33 months) Study 16 "We limit our sexual life because I am a (cancer) patient. If I feel physically fine, we occasionally satisfy our sexual needs. However, we usually do it at longer intervals, unlike what normal people do." (57 years old, 54 months) Study 16 "Although I seldom do household chores nowadays, I feel that the burden on my family may be lessened if I can take good care of myself." (57 years old, 54 months) Study 16 "In the beginning, it was very difficult for me that my husband had to clean the house and I could only look on. I sat there crying because I like to clean the house and I could do nothing." Study 17 "For him, I regret. I do not feel the desire to have sex anymore. That is over. And then I think: "He is normal". I do not feel normal anymore. I do not feel like a woman anymore." Study 17
The use of coping mechanisms to ease the experience	**Active coping** "(…) I am pretty healthy. Ok, I cannot do everything that I used to do in the past, but that doesn't make you less healthy than someone else. The advantage of everything that happened to me is that I pay more attention to myself. I rest more often, try to live in a more relaxed way, take more time for myself and set my boundaries. That's living healthy in my opinion." Study 13 "It does put up weight, I swim every morning, if I don't swim I'd try go for a walk, you have to watch what you eat as well, it would bother me, but it wouldn't bother me enough to stop taking it. It is possible to lose the weight; it's just harder." (P22) Study 15 "I read on the internet about looking after myself […] I eat much healthier now, and avoid alcohol and caffeine. A bit boring, but it helps. The side-effects are less now." [P7 adherer] Study 19 "I wanted to be able to do something for myself. I wanted to be able to adapt and have some way of coping with the side-effects. I started by eating more healthily. It was a way of taking back control." [P5 adherer] Study 19 Self-motivation "There are parts of me where I am dying to finish tamoxifen to see if I feel a bit normal again. But I just kept that focus that, I really don't want this to come back especially when I've two young children, I can put up with bone pain. I want to feel for myself that I gave this hundred percent." (P14) Study 15 **Seeking support** "It is very important to have a support network" (interview 12) Study 5 "The goal is to heal, or to have a better quality of life, people does their best, but one needs to start by helping herself" (interview 9) Study 5 "It really helpful if you have someone that can support you and give you literature, give you researches and put you in touch with somebody else that have gone through." Study 10 "I ring the doctor, I ring friends, I ring other people to find out. I went back to the hospital and they told me to start taking primrose oil. I'm still on it. Now it's more manageable. I cope better." (P5) Study 15 "I went to a really good (support centre). It is lovely for people who are in a time in their life, when it is like the rug has been taken from underneath you. I feel that if you go to the things that are in place to help you, then you have a better chance of coming along the road and coming out the other end and thinking yeah, I'm good now." (P11) Study 15 **Maintaining a positive attitude**

	"People say oh you're so positive, of course I was positive because the alternative is having a chat with the undertaker. And I suppose on the tamoxifen I feel I'm avoiding that. I think l if I was off the tamoxifen I could be cognitively quicker, I could lose the weight and I would be probably amazed at how better I'd be if I was two or three stone lighter but I would be afraid to take that risk." (P7). Study 15 "Sometimes, I feel a bit down. I remind myself that I should grasp my current happiness. I shouldn't worry about the future because nobody knows what will happen." (52 years old, 37 months) Study 16 "Suffering from cancer is unfortunate, but I am fortunate to meet new friends here. When one of us has small things to celebrate, we usually chat or gather together. We quickly forget our negative thoughts." (65 year old, 53 months) Study 16 **Meditating and praying** "I like walking or meditating. They are things that I learned to do, which I find absolutely brilliant for centering myself. I never kind of panicked or thought why me." (P11) Study 15 "Puck yourself up, go out for a cup of coffee and if I got the table at the window and the tide was in and the winter sun coming, there is nothing as nice. That was my therapy and I made it my own." (P16) Study 15 "Every time I encounter difficulties, I pray for God's help. I pray by singing as I work, and I feel relieved and peaceful." (51 years old, 17 months) Study 16 **Acceptance** "As for the tablet, I now accept it, always hoping that everything will be fine." (interview 7). Study 5 "I have many circulation problems and I have gained weight, that's true But maybe these things cannot all be attributed to the treatment We know there are phases in life, physical changes that occur at menopause, and well, we have to accept it You have to tell yourself: 'you are not 20 any more!' I will be 50 years old in a few days, that's not easy to accept With the disease that has added on 2 or 3 years, it's even more difficult But in the end, the side-effects, I guess once you have accepted them, you feel better! I feel the way you cope with this treatment is part of the treatment (E, aged 49, 2 years of treatment)" Study 9 "There's an expression in Japanese that says, 'It can't be helped.' So you're supposed to have the strength to go through it because it can't be helped.…It's not something that I can do anything about. I can't stop it. I can't change it. So, I have to deal with it." Study 14 "Suffering from cancer is unfortunate, but I am fortunate to meet new friends here. When one of us has small things to celebrate, we usually chat or gather together. We quickly forget our negative thoughts." (65 year old, 53 months) Study 16 "There's days you are exhausted with it all, these sweats, just go away. I had me hard time, can that not be it. Mentally I just (pause), say it's coming on me, just deal with it, take a cold drink of water and relax then. This is gonna happen to you but it'll pass. You can't fight it, you just have to let it happen because it's just gonna come" (P16) Study 15 "I'm quite happy now, after the cancer. I would have been a hyper person, doing this, doing that and I could never settle but I find that I'm settling now, a bit calmer. It was never important." (P16) Study 15 **Humour** "I've worked with lots of women, and we all say (laughter) estrogen, the menopausal breakdown. But, I have days when I just... can't remember things like names or specific words for thoughts... And I'm usually really good. I love words, and I'm usually pretty good with them. But, I just have days when I can't, and I'm not as articulate... I just finished helping with the summer camp and we had about 18 college counselors... I remembered all their names, and once in a while I'd completely blank... but I had a notebook, I had my cheat sheet" Study 11 "You kind of get used to it and you laugh it off. If you're sitting with your friends having a cup of coffee your saying I'm going, I'm going, here we go girls (laughs), I'm like a traffic light." (P16) Study 15
Trying not to forget by making adherence to the treatment a part of the daily routine	"Got the routine, I take the dog out, come back, have all the, have a wee drop breakfast and have the rest of the pills " Participant 22, agerange 50–64, letrozole Study 1 "I was away to New York before Christmas time, well, in November So, I had toI was trying to, I was taking itthrough the night Because I wanted to keep it in the 24 hour clock So, it wasI think it was four o'clock in the morning" Participant 5, age range 50–64,tamoxifen Study 1 "If I'm day shift I am taking them at seven, if I am night shift, I'm taking them at 8 in the morning So I am keeping them as near as possible to the twenty four hour period" Participant 16, age range 50–64, tamoxifen Study 1 "In the morning my routine is I'm going to go to the kitchen, I'm going to get my coffee ready, I'm going to get out the pills and then I'm going to drink them with water and then I'm going to have my breakfast and my coffee" Study 4 "I have learned to keep it near the cup of coffee...I remind myself by keeping it in view then, as soon I have taken it I put it away to avoid taking it twice" (interview 26) Study 5 "I tell myself that instead of the pill I am taking tamoxifen It's a hormonal treatment, and it is one pill a day I take it in the same way as I took my pill in the evening, before I go to sleep I usually put it on my bedside table, so I will not forget to take it" (I, aged 36, two years of treatment) Study 9 "About never forgetting the medication "Cause I take it with my morning vitamin, my calcium, and fish oil." Study 11

	"Every morning when I get up, before I do anything else, I take my tablet out and I put it there and get my breakfast ready and then while I'm having my breakfast I take it." (P11) Study 15 "I leave it beside my prunes in the morning. And I take prunes every morning so I leave it up in the press beside the prunes." (P20) Study 15 "I haven't missed any because I have a little box with Monday, Tuesday, Wednesday, Thursday on it and I take it every night at the same time, in around the same time every night and I'd know if I've missed it." (P22) Study 15 "You get yourself into a routine and I have a routine, I take it first thing in the morning, I have me juice and me tamoxifen and that is the start of the day. And you would nearly miss it now, if you didn't take it." (P1) Study 15 "Tablets are part of your life, you won't forget. It's part of your routine, whatever I do, wherever I go, the first thing you get up in the morning, in your head, you get in the routine that it's very hard to forget." (P5) Study 15 "I go out to the kitchen every night before I go to bed and take it with a drop of water. It's the last thing I do, more or less, brush the teeth and everything else. I value it, I actually do value it. I think when something is important enough to you, you do it, like brushing your teeth at night." (P30) Study 15 "I was taking the Tamoxifen in the morning, or if I didn't take it in the morning I would remember it by twelve o'clock, if I forgot it at least I'd remember it by dinner time. Then I was forgetting to take them. I did use my alarm and then you'd turn it off and say I'm taking it now, and you still wouldn't go to take it, like if you were doing other things." (P17) Study 15 "In general it's breakfast time and I'm on my way out to school or at the very latest I would take it is 8 pm. I will not take it after 8 pm because I have to take it early again the following day. I'd be terrified to take the two together so I just leave it." (P3) Study 15 "I usually take it, after breakfast, in the mornings if I remember but if not any time during the day. If I was at home, I would definitely go and take it when I remember or if I was outside or out in work, I would make a mental note to take it, when I got home. At the start, I would keep forgetting, it happened maybe a few times a week, but now I've got better. I never took medications really, unless the usual thing, like the flu, antibiotics. This is the longest I've been on medication." (P10) Study 15 "On Sunday because I'm going to church for communion and I don't have my breakfast or coffee I forget. And I come back after church and I forget." (P4) Study 15 "If you had visitors or if your routine changed or if there was something going on, I might turn round and oh God I didn't take any of my tablets." (P7) Study 15 "If there's something big on or I have to bring the young one to university and then by three o'clock I could remember to take it or I might not remember to take it. But I'll have to leave it to the following day. It would go out of my head to take it." (P3) Study 15 "I asked myself what do I do everyday of my life? At breakfast, my jar of peanut butter . . . Every morning, it is there." Focus Group 3, Participant F. Study 21
Consequences	
Adhering to the treatment	"As for the tablet, I now accept it, always hoping that everything will be fine." (interview 7). Study 5 "I am certain that I have done all the right things. . .after all, it is true that it makes me aware of the situation, but it does so by making me aware of the past and also the present and the future..." (interview 18) Study 5 "It's as if it acts as a protection cover. . .now I take it and I hope it works. . .it protects me." (interview 10) Study 5 "These medicine are beneficial on the one hand and harmful on the other, but they help us to live longer and it is important to be aware that this is a medicine that helps to live. . .that's why one must take it. . .one must fight until God gives us the possibility" (interview 20) Study 5 "I'm living the therapy peacefully, one manages it with serenity. I live everything with great naturalness and serenity and I can manage everything very well" (interview 3) Study 5 "I think taking the pills on time is the key to efficacy" Study 6 "You learn to live with it...as it could save my life" (interview 22) Study 5 "I have been very open about my breast cancer. This encouraged the people around me to also talk with me about breast cancer. I got many warm reactions. The chemotherapy made me very ill, but it went away. Starting with endocrine therapy did not pose a problem to me. I am happy that there is something that I can do to prevent metastatic cancer." Study 13 "To me, endocrine therapy was just the next step in the sequence of surgery, chemotherapy and radiation therapy. When I started using endocrine therapy, I thought I had gone through the hardest part of my treatment and I considered endocrine therapy as a protection for the years in the near future. Although, I still feel the same about that, endocrine therapy has a big influence on my life. On the positive side, I have not metastatic cancer or recurrent breast cancer. The difficult consequences of Tamoxifen and later also Arimidex were the severe depressive episodes. I could not adjust to them, whereas I had accepted many other adversities. My oncologist convinced me to continue." Study 13 "It is THE treatment, that's it. I did not have anything else. I didn't have any treatment besides this. So it was awful, but I was obligated." Individual Interview, Participant C. Study 21
Having a drug holiday every now and then	"I've sort of assumed that if you're taking a drug for five years it isn't going to really make a lot of difference you know it's not as if these poor old cells are suddenly going to start pumping the stuff out because you took it eight hours late" Participant 23, age range 50–64,letrozole Study 1

	"I was trying to keep it going till I got to the clinic but because I felt I couldn't drive my car I stopped it because it was only about ten days before my clinic appointment But you know I mean I knew that really ten days off it wasn't going to make any difference you know in the long term, so then I got tamoxifen and I'm fine with that" (Participant 24, age range ≥65, letrozole then changed to tamoxifen) Study 1 "I chose to continue on But I must admit I don't take it every day" FGB Study 8 "So I think if you're taking Arimidex_ over years, they're [adrenal glands] not going to all of a sudden, if you miss one, they're not going to all of a sudden get back going again when they've been put to sleep as... for as long as they have been... I mean if you skipped a whole month... or even a whole week... that might be a different story...' cause then they'd start getting their act back together." Study 11 "Maybe I won't take that today and see if it helps," Study 14 "The odd time I mightn't remember I took it that morning and I might take it again but now I'd say to myself if I can't remember, a day won't matter so I will take it tomorrow." (P10) Study 15 "I've got to the stage where sometimes I'll just give it a miss. . .I just get so fed up of taking it, I just want to give myself a break." (Miriam, 41, non-adherent) Study 18
Committing to finishing the whole duration of the treatment	"I'm going to take my medication, regardless I mean I'm just going to take it I'm convinced that taking it for five years with the other therapies that I've had increases my survival rate up to ten years, but having talked to other women who have quit, they just really couldn't get past the symptoms and I understand that" Study 3 "wanting to get to the finish line." Study 11 "I would never dream of quitting" Study 11 "I truthfully want to do the five years. I want to complete the program as is," Study 11 "I just wouldn't stop taking it now. No, definitely not. I'm just going to have a few sweats and that." (P22) Study 15 "I wouldn't go off it to save my life, excuse the pun. Definitely, there's no way I would not take it, not in a million years, absolutely not, I wouldn't even contemplate it." (P30) Study 15 "I just want to get this over me. It was the same with the chemo, every week me goal was to get another one behind me, and it's the same with the tablets. Because you won't find five years, sure there's nearly a year now." (P16) Study 15 "There are parts of me where I am dying to finish tamoxifen to see if I feel a bit normal again. But I just kept that focus that, I really don't want this to come back especially when I've two young children, I can put up with bone pain. I want to feel for myself that I gave this hundred percent." (P14) Study 15 "I never considered not taking it because I wanted to do all I can do to make sure I'm the one that wins this battle, not the cancer." (P15) Study 15 "If me arm has to get amputated I'll still be taking tamoxifen. I won't be chickening out halfway through it. I'll be the hormonalist, crankiest, sweatiest, narkiest, but I'll still be taking them." (P15) Study 15 "You need to know you've given it your all and your shot at keeping this away and there's nothing you can do then, but at least you know you've done your best." (P14) Study 15 "The AHT is a protection against cancer. I think it will be hard for me the day I have to stop the medication. Suppose I relapse when I am no longer taking that medication. Now the medication gives me the feeling I am protected against recurrence." Study 17 "I know I have no other choice than taking the AHT medication. It protects me against cancer and we can be reasonably sure that there will be no relapse if I take this medication for five years. I have to continue now because there is always a little voice that says: "You have had cancer"." Study 17 "I hope that those five years will pass quickly. In September it will be two years, then another half year and then I am halfway. Once I am halfway, it will pass more quickly, so I will be glad to be halfway." Study 17 "Whether like you say with me it would have come back, I just don't know. I'd rather take it than not." (Ellen, 50, adherent) Study 18 "In one way I was quite looking forward to stopping, but then as it got nearer, I thought, ooh, it's like a safety blanket being taken away isn't it?" (Julie, 61, adherent) Study 18 "I never stopped taking it because I thought the nausea and things like that, come on its keeping you alive so stop moaning." (Michelle, 77, adherent) Study 18 "I just felt like this was what I had to do to keep the cancer from coming back, and I'll do what I have to do." Study 20 "I mentioned it to [my doctor], but I knew it was just one of those things I would have to cope with, so I just did." Study 20 "Well, the only thing l can think of [that was an important benefit] is that I have a process in mind that I'm not gonna get [cancer] anymore. That's the way I feel, that I'm here because of a reason, that l have a lot of things to do. I have a new granddaughter that I want to continue being with her. I know I'm not gonna get cancer." Study 20 " . . . All the effort made by everyone around us to support us. What's taking a pill? We owe them that." Focus Group 1, Participant C. Study 21
Suffering from the side-effects of the treatment	"If I was a car engine it had just sucked all the oil out of my entire body so my knees, my shoulders ache like they've never ached before" Participant 8, age range 50–64, tamoxifen Study 1

	“it was affecting my life quite badly; I mean you go out for a meal and you are sitting and the water is lashing off you, and you have only had a cold drink It’s really quite debilitating at times” Participant 16, age range 50–64, tamoxifen Study 1 “Anyway immediately I noticed the hot flushes and they were terrible to start with I was sometimes getting 7 or 8 a night and just drenched and just waking up, I couldn’t sleep” Participant 14, age range 50–64, tamoxifen Study 1 “I had quite a busy jobSo I stopped that so you know I really could pretty much say I’m doing hardly anything and yet I’m still exhausted all the time” Participant 18, age range 50–64, letrozole Study 1 “We’re having to downsize our house so that we can accommodate the fact, because I would rather live in a smaller house costing less money, so that I have the option that if I’m still not well enough I don’t have the pressure of having to go back to work” Participant 26, agerange 50–64, tamoxifen Study 1 “Well, I felt more emotional, I suppose I felt more PMT-ish I feel I get a bit panicky, but that’s, maybe, just old age, I don’t know Because you can’t blame things on what you’re taking” Participant 1, age age ≥65, anastrozolewhich was changed after 3 months to tamoxifen followinga bone scan Study 1 “I am more forgetful I work harder at work to do the same job that I used to just do It’s harder for me to stay focused, to concentrate, to think clearly, to remember everything” Study 3 “Because of the side-effects and my hands I’m an artist I’m a floral designer I couldn’t I still can’t pick up a straight pin I can’t pick up anything small like a needle” Study 3 “I didn’t expect the night sweats to be so bad I didn’t expect them to interfere with my sleep” Study 3 “I wouldn’t have ever thought that it would interfere so much that I don’t feel like myself I don’t have the energy I can’t sleep I’m having trouble at work” Study 3 “There are days that all of you is in pain, all the body… A pain that you don’t know what is hurting And it is so horrible … you try to be still so it doesn’t hurt You can’t cook, you can’t clean, you can’t even bathe because…the pain is in all your body” Study 4 “There are days that I feel very tired, I don’t want to get out of bed, there are also days that I feel a lot of pain in my muscles, all my body hurts, very depressed, depression, I feel like crying” Study 4 “And she [a nurse] told me, she said yeah that’s Tamoxifen That’s one of the side-effects So I told her wow, …I never knew…Because the first time when I was on the Tamoxifen, it’s like sometimes I would be in a rage” Study 4 “I was on crutches I was using a cane I couldn’t get out of a chair because my knees were so bad I mean they still are, but they’re 100 % better, and it’s been a year and a half, and I went on a site called askapatientcom I read case histories from age 37 to 73, who had been on just Arimidex, and I was blown away at how many women have suffered this knee problems… And so… I Googled Arimidex and started to read about it… I mean I have a folder that’s probably this thick about it It’s nasty It’s terrible stuff” Study 4 “It is an experience that led me into a deep depression, that led me down” (interview 4) Study 5 “The only thing that bothers me is forced menopause, hot flashes. . .and the loss of sexual desire... This is not a positive experience” (interview 27) Study 5 “great impact on sexual life because of vaginal dryness... I don’t know how to describe it. I’m used to face and manage the situations that are hard, but it is upsetting” (interview 24) Study 5 “I don’t want to be excessive but my hepatic steatosis worsened and it is altering all my liver values. I never had so high transaminases and gamma glutamyl transferases. Then there are also other effects that I do not know precisely to what are associated because I also take ‘Enantone.’ For example, I also have joints and bone pain, above all at the level of the sacrum that do not allow me to stay sitting for a long time; then I also gained weight,. .. awful hot flashes also at night. . .at any time!” (interview 22). Study 5 “It is disabling...the physical pain is not well accepted at all” (interview 14) Study 5 “I feel very ambivalent about this treatment at the moment I have put on 5 kg since I started, it worries me a lot Then I had a check-up with the gynaecologist which showed that tamoxifen has caused a cyst on an ovary So tamoxifen wants to stop my hormonal system from working, but the cyst has made the system want to work I found myself 10 days ago with my body really upside-down My belly looked as if I was 5 months pregnant, inflated, hard, horrible At the same time, the blood tests showed that my hormones are a little upside-down Since I started taking this medication, I have also had a pain that I did not have before in the breast, and very poor circulation in the legs I have been having a lot of hot flushes too That’s horrible, it’s like a wave, all the points on your body you can imagine are sweating When that happens, it is uncontrollable, and you feel terribly unclean” (W, aged 50, 9 months of treatment) Study 9 “The hot flushes, that’s what made me suffer most It is the most difficult thing to cope with I know there is no solution: I am not allowed to take any of the effective ones: oestrogen I can’t take, and soya products I can’t take either The only thing that I am allowed to take is abufene, but it makes absolutely no difference It’s the same with homeopathy” (G, aged 52, 10 months of treatment) Study 9 “One month after undergoing chemotherapy, my periods stopped And since then, things have not been back in working order The question is therefore: is it the tamoxifen which goes on stopping the periods? Or the pre-menopause, as the doctor said? I was taking hormones But as the hormones were stopped and I was given tamoxifen, the hot flushes started to occur again Was that due to stopping the hormone treatment? Was it due to tamoxifen? That is the big question I don’t know I really don’t know” (M, aged 49, two years of treatment) Study 9

	"I put on weight, but maybe it was because I stopped smoking? As far as hot flushes are concerned, I had some before, but right now I am having more and more Every hour, suddenly I'm in a sweat! Does tamoxifen increase them? I wondered whether stopping smoking did not increase my hot flushes two-fold, as well Or going back to work In addition, the weather is so hot right now" (R, aged 46, 6 months of treatment) Study 9 "To kill off the female hormones that I produce is unacceptable to me It is an additional mutilation after the mastectomy, a loss of my female image I was born a woman and I want to remain a woman With this treatment, we have to make up our minds to take it every single day for five years Five years is a long time, and these five years are important when you are not far from the menopause like me, because there's no turning back We are pushed into the menopause without being able to go back It also means that we will not have access to alternative treatments for menopause So we will age more quickly" (I, aged 50, 15 months of treatment) Study 9 "See, that's what I was talking about, those sexual issues." Study 10 "Because for me, especially being young or old, I guess it doesn't matter. You worry about the body image." Study 10 "I guess I didn't expect to feel as weak." Study 10 "It makes me feel better to know that fatigue is an effect." Study 10 "You might done lost a lot of weight and you might be looking bad." Study 10 "I told them, I'm still fat as you know what. I ain't lost no weight. I still look good, just ain't no hair. I said, you don't kill no hog for no hair, baby you want the meat." Study 10 "Overall it feels like a torch... the chest area and face and forehead; my forehead's like soaking wet ... they come on real fast and last about a minute or two... during the night I might wake up it seems every two hours... like at midnight, two o'clock, four o'clock, six o'clock, and you know it wakes me up and sometimes I can't go back to sleep so that is an additional problem." Study 11 "The only thing I do have a problem with, and I have noticed it, is my memory. Now I'm remembering a lot of things... today, talking to you, but if somebody said, "Well, I told you that yesterday," or "Don't you remember I..." "I can't remember." I have to really think, and that scares me. I mean I had a bad memory before (laughs)... but it, it is worse. It is, it is worse." Study 11 "I've worked with lots of women, and we all say (laughter) estrogen, the menopausal breakdown. But, I have days when I just... can't remember things like names or specific words for thoughts... And I'm usually really good. I love words, and I'm usually pretty good with them. But, I just have days when I can't, and I'm not as articulate... I just finished helping with the summer camp and we had about 18 college counselors... I remembered all their names, and once in a while I'd completely blank... but I had a notebook, I had my cheat sheet" Study 11 "The main side-effects are stiff joints, aching muscles and indeed [in response to another participant] less sexual desire. The consequences can be annoying. I used to walk long distances with friends but I cannot do this anymore. This is also disappointing from a social point of view." Study 13 "What is important for me is to go back to my lifestyle, which is very active. And with the side-effects, I would have been on that couch." Study 14 "And I have two, three grandchildren. I love children…. So, when I see them, I want to play with them … but physically I can't do it. So, that makes me—really upsets me. I think that's the thing." Study 14 "I understand that I could take it as much as I could bear it and if it's helping me. Well, if I start getting, you know, my bones deteriorating and things like that, losing a lot of hair, where I could see physical change in me, I will know that I will stop it." Study 14 "I am unable to undertake too heavy/many physical tasks. I should perform light work only. For example, I easily feel tired when cooking. I have to take a break and lie down on the bed for 15 minutes. After boosting my energy, I get up and continue to cook." (65 years old, 53 months) Study 16 "My arm on the affected side is too weak to carry things. If I hold on to something, walk for a short distance, or do more household chores than normal, my arm becomes swollen. Now, I seldom use my arm and perform less housework." (63 years old, 18 months) Study 16 "I think they have explained too little about side-effects. They have actually minimized them, which makes them worse than I imagined them to be. Now I have to learn to deal with it after I have experienced them and this is very difficult." Study 17 "I turned into a monster over the few months following chemotherapy. I thought it was the stress of what I had been through, but it went on and on. I read on the internet that it could be the tamoxifen. I felt depressed and would swing into a temper for no reason." [P22 nonadherer] Study 19 "It [tamoxifen] altered my mind […] I felt almost suicidal with it. I didn't realise it was the drug until I got sick and didn't take it for a week. I felt so much better." [P21 nonadherer] Study 19 "And I didn't want to go out and I became quite withdrawn really, so no, it wasn't acceptable." [P20 nonadherer] Study 19 "I didn't really feel like doing anything. I carried on going to work, that was fine. I just couldn't be bothered to do anything out of work – like meet friends, see family. I just wanted to vegetate at home." [P24 nonadherer] Study 19 "I knew quite a few and people who knew women who had put on a lot of weight which they blamed on the tamoxifen […] How am I going to teach [aerobics] when I look like a balloon? […] So that was a problem and that was all part of the hysteria." [P27 nonadherer] Study 19 "I got thrown into the menopause. […] [O]ne of the things that upset me most at the time [was that] I lost all interest in sex overnight – it didn't help my husband as you can imagine." [P30 nonadherer] Study 19

	"I didn't even know my body was going to go through that. It hit me like a boom." Study 20 "I already had osteoporosis to start with, and the Femara® certainly did not help." [My doctor] told me I would probably have night sweats and hot flashes, but that's all I really expected. I didn't expect the [severe side-effects] I had. … It started with pain in my shoulders, and then it moved to my jaw. Eventually, it moved to every joint in my body." Study 20 "I just don't feel exactly like myself [on Arimidex®]. I don't feel real clear-headed, and I feel groggy a lot of the time. If you're not sleeping well, you don't know if one thing causes the other." Study 20 "I had extreme joint pain, back, knees, hands, feet. I had swollen knuckles. My ring size went up like at least two sizes. I couldn't wear my shoes. . . . It was bad." Study 20 "I had . . . what I have come to find out, as every conceivable side-effect that the drug has. . . . It started out with pain in my shoulders, and then it moved to my jaw. Eventually, it moved to every Joint In my body. Every muscle In my body hurt. You could touch me, and I would bruise, and when I would bruise, I went pale. I . . . for an example, I had a toe that rubbed in a shoe, and it got black from that, and it remained black for the entire nine months that I was on tamoxifen." Study 20 "I had such chest pain I thought I was having a heart attack." Study 20 "My fingernails became brittle. I also had some hair loss." Study 20 "Well, just generally, I had some hair loss. I had dry eye. I had vaginal dryness. The kinds of effects that losing all of your hormones does to you." Study 20 " . . . the hot flashes. I would wake up during the night and be drenched. I skipped one month [of AET]." Focus Group 3, Participant F. Study 20
Being surprised by the difficulty of the treatment and the severity of the side-effects, thus, finding adherence to be more difficult than originally though	"I wouldn't have ever thought that it would interfere so much that I don't feel like myself I don't have the energy I can't sleep I'm having trouble at work" Study 3 "And she [a nurse] told me, she said yeah that's Tamoxifen That's one of the side-effects So I told her wow, …I never knew…Because the first time when I was on the Tamoxifen, it's like sometimes I would be in a rage" Study 4 "I guess I didn't expect to feel as weak." Study 10 "I think they have explained too little about side-effects. They have actually minimized them, which makes them worse than I imagined them to be. Now I have to learn to deal with it after I have experienced them and this is very difficult." Study 17 "I was prepared for anything, except the fact that I would go into menopause from one day to the next. Nobody had informed me about it. I was very, very disappointed and saddened. People say it had to happen, which is true, but that was the furthest thing from my mind. You are losing part of your femininity. For me that was the most difficult part of the entire treatment. . . I did have everything, but that was the worst for me. And maybe because they did not inform me in advance." Study 17 "I think there should be more help, psychologically, with side-effects of tamoxifen. I think people ought to be warned." (Kate, 52, non-adherent) Study 18 "I would have liked more information to prepare for the side-effects. I was given lots of information about the side-effects of chemotherapy and how to manage them, but I wasn't expecting the side-effects of AET. So perhaps that made it worse." [P1 adherer] Study 19 "If someone had said to me, these are the side-effects that other women report – say 20% of women have this side-effect, and if you get it come back and we can help you with it, then that would have been great. It's a lack of information that's the problem." [P26 nonadherer] Study 19 "I didn't even know my body was going to go through that. It hit me like a boom." Study 20
Restriction of social activities	"The main side-effects are stiff joints, aching muscles and indeed [in response to another participant] less sexual desire. The consequences can be annoying. I used to walk long distances with friends but I cannot do this anymore. This is also disappointing from a social point of view." Study 13 "We have not felt normal since we suffered from this illness (cancer). What can we do for survival? We have been mentally exhausted. We can't live without medicine. We need regular exercise. We can't go outing because we need to take herbal medicine twice a day. We can't also eat outside because foods are unsafe and unhealthy. We have no choice if we get this illness." (49 years old, 33 months) Study 16 "And I didn't want to go out and I became quite withdrawn really, so no, it wasn't acceptable." [P20 nonadherer] Study 19
Side-effects of the treatment, old age and other medications get entangled	"I think it's so hard to know what is causing what and like I said if you didn't have that other things factor in, age and all that, but I do think the medications, like you say [referring to comment by another participant], exacerbated" Study 3 "One month after undergoing chemotherapy, my periods stopped And since then, things have not been back in working order The question is therefore: is it the tamoxifen which goes on stopping the periods? Or the pre-menopause, as the doctor said? I was taking hormones But as the hormones were stopped and I was given tamoxifen, the hot flushes started to occur again Was that due to stopping the hormone treatment? Was it due to tamoxifen? That is the big question I don't know I really don't know" (M, aged 49, two years of treatment) Study 9 "I put on weight, but maybe it was because I stopped smoking? As far as hot flushes are concerned, I had some before, but right now I am having more and more Every hour, suddenly I'm in a sweat! Does tamoxifen increase them? I wondered whether stopping smoking did not increase my hot flushes two-fold, as well Or going back to work In addition, the weather is so hot right now" (R, aged 46, 6 months of treatment) Study 9 "I have many circulation problems and I have gained weight, that's true But maybe these things cannot all be attributed to the treatment We know there are phases in life, physical changes that occur at menopause, and well, we have to accept it You have to tell yourself: 'you are not 20 any more!' I will be 50 years old in a few days, that's

	not easy to acceptWith the disease that has added on 2 or 3 years, it's even more difficult But in the end, the side-effects, I guess once you have accepted them, you feel better! I feel the way you cope with this treatment is part of the treatment" (E, aged 49, 2 years of treatment) Study 9 "It's very hard for me to pinpoint what's causing what because I have all of these different [health conditions]." Study 14 "There is a little joint problem I'm having, and it's probably letrozole based. I say probably because I'm aging and I do have a little arthritis in my spine. But when I first wake in the morning, I'm more stiff than I have ever been, and we seem to attribute it to letrozole. Whether that's fair, I'm not sure." Study 14 "I have had depression [before cancer]. And, of course, the whole process doesn't exactly lead to …. [chuckles] So, I don't know if that's a side-effect of the drug or not.… It's really hard to separate that [depression] from the actual cancer, so I don't know." Study 14 "I am more fatigued, but that's due to the aging. Every normal person gets more tired by the evening." Study 17 "I thought it was the long-term effects of chemotherapy, so I thought it would improve. When it didn't long-term, I began to realise it was possibly the hormone therapy." [P17 adherer] Study 19
Cancer and being sick keep on lingering throughout the treatment	"I still feel like I have the disease, even though it has been a year since surgery and 6 months since the start of hormone therapy. While I feel so lucky knowing that everything went well, the presence of the disease still lingers on. . ." (interview 15) Study 5 "I have lost the ignorance of childhood. When I become aware of a bodily sensation, I always think it is cancer. The least thing I become aware of, I think it's a tumor." Study 17 "Everyone acts like the treatment is over. It does not feel like the treatment is over. As long as I have to take this medication, I am not like before." Study 17 "I know I have no other choice than taking the AHT medication. It protects me against cancer and we can be reasonably sure that there will be no relapse if I take this medication for five years. I have to continue now because there is always a little voice that says: "You have had cancer"." Study 17 "I absolutely hate taking this tablet. It's a very powerful drug. It's not just the side-effects. It's a reminder of what I had." (Lauren, 62, adherent) Study 18 "I find it very difficult to be honest. . .I think the thing is anything that you find that you feel that is not right in your body then you start thinking 'I wonder if it's something serious'." (Arlene, 62, adherent) Study 18 "That would be my biggest fear is, it's not, I suppose if it's going to come back it's possibly when, but I can't live my life like that. So I kind of like have to block it and just continue as much as I can." (Elisabeth, 37, adherent) Study 18 "Someone said to me it's like having a sword dangling above your head, and it is. You just feel like tomorrow you don't know what's going to happen. It's always there in the back of your mind." (Kate, 52, non-adherent) Study 18 "It's like a trace of what we've experienced, like a passport that you always have on you." Focus Group 4, Participant M. Study 21
Forgetting to take the treatment as prescribed occasionally	"I was away to New York before Christmas time, well, in November So, I had toI was trying to, I was taking itthrough the night Because I wanted to keep it in the 24 hour clock So, it wasI think it was four o'clock in the morning" Participant 5, age range 50–64,tamoxifen Study 1 "If I'm day shift I am taking them at seven, if I am night shift, I'm taking them at 8 in the morning So I am keeping them as near as possible to the twenty four hour period" Participant 16, age range 50–64, tamoxifen Study 1 "There are quite a few times that I forgetThere is sometimes that I go to the box and I have missed the day before, but I am bad for that, because if I discover that, I take them, and then I take them again, twelve hours later" Participant 15, age range ≤49, tamoxifen Study 1 "I tried doing it in the morning, but I'd forget it because I'd be too busy doing…other stuff" Study 4 "I have the alarm on the phone that reminds me...a reminder...From a practical point of view 1 can than suggest to those, like me, who must take this drug, to use this reminder with the alarm clock, possibly on the morning, so you must get up to switch off the alarm and you are stimulated to take the drug" (interview 10) Study 5 "I write the date on the package in order to count the tablets just in case" (interview 3) Study 5 "In case I forget, my husband reminds me" (interview 7) Study 5 "... My husband had to get them out... Arimidex_ people ought to know that that is not acceptable. (Laughter) Maybe they found that out... but I'll tell you that was the only time that I considered stopping. Because I have arthritis in my hands... and they're old hands... it was very, very diffi cult. I couldn't put it through, you know, so I tried to use a penknife, I tried to flip up the little foil thing... and sometimes I'd try to slice off the bubbles like this. (Gestures). It's just hard. I couldn't do it. I was in that AIM Study and I had the little bottle, and I swear I took it every day, but there was a few times when she (study nurse) put it on the little machine to see that I had missed it a few times. Now last night I went to bed and I remembered about 1:00 [AM] and I came down the steps and took it." Study 11 "About never forgetting the medication "Cause I take it with my morning vitamin, my calcium, and fish oil." Study 11 "When I started it, that's when I put into my day [pill minder]... I've had no trouble remembering to take it, and that seems to be a good time [after supper] since its after my work day, except when I have a meeting, I don't forget." Study 11 "Sometimes I might play the 12 hour shuffle if I know I didn't take it the night before... maybe I'll take it in the morning, and then at bedtime, so it's probably putting two in one day, but trying to spread them apart, so it's not quite the same." Study 11

	"I fill my box up every Sunday because it begins on Sunday, then it ends on Saturday, at the other end, so every Sunday I'd sit down and I'd fill the box and then I'd check to see what's left, 'ah yeah, I have another week', and I'd go to the chemist." (P22) Study 15 "Every morning when I get up, before I do anything else, I take my tablet out and I put it there and get my breakfast ready and then while I'm having my breakfast I take it." (P11) Study 15 "I leave it beside my prunes in the morning. And I take prunes every morning so I leave it up in the press beside the prunes." (P20) Study 15 "I always have box at home, 28 days, 15, 20 days, I have extra. I make sure I have at home one box and I have 1 or 2 in the pharmacy that I'm not stuck." (P5) Study 15 "I never forget, it's very important, if I go away I put one set in my case and I will make sure I have a set in my bag. If I'm away on holidays I'll make sure if one got lost that I won't be without it." (P30) Study 15 "I've tablets everywhere, I've a drawer in my dresser, that's the tablet drawer, in me Mother's house, but I generally have a strip of it in my wallet all the time. If I go abroad it comes with me, everywhere I go, it's part of me, it's like packing your toothbrush, you pack your medication." (P15) Study 15 "I fill my pill box up on a Monday and I put all my tablets in and then just in case, you take it in the morning and then you say to yourself, did I take my tablets, I go back and look at today and say I did." (P5) Study 15 "I can't forget to take them, sometimes I used to say 'did I take that tablet?', because it'd be in my head all the time to take it. Then I'd know how many tablets was in me thing and I'd know I'm after taking it, but I think it's just in your mind, you have to take it for yourself." (P26) Study 15 "I haven't missed any because I have a little box with Monday, Tuesday, Wednesday, Thursday on it and I take it every night at the same time, in around the same time every night and I'd know if I've missed it." (P22) Study 15 "You get yourself into a routine and I have a routine, I take it first thing in the morning, I have me juice and me tamoxifen and that is the start of the day. And you would nearly miss it now, if you didn't take it." (P1) Study 15 "Tablets are part of your life, you won't forget. It's part of your routine, whatever I do, wherever I go, the first thing you get up in the morning, in your head, you get in the routine that it's very hard to forget." (P5) Study 15 "I go out to the kitchen every night before I go to bed and take it with a drop of water. It's the last thing I do, more or less, brush the teeth and everything else. I value it, I actually do value it. I think when something is important enough to you, you do it, like brushing your teeth at night." (P30) Study 15 "I was taking the Tamoxifen in the morning, or if I didn't take it in the morning I would remember it by twelve o'clock, if I forgot it at least I'd remember it by dinner time. Then I was forgetting to take them. I did use my alarm and then you'd turn it off and say I'm taking it now, and you still wouldn't go to take it, like if you were doing other things." (P17) Study 15 "In general it's breakfast time and I'm on my way out to school or at the very latest I would take it is 8 pm. I will not take it after 8 pm because I have to take it early again the following day. I'd be terrified to take the two together so I just leave it." (P3) Study 15 "I usually take it, after breakfast, in the mornings if I remember but if not any time during the day. If I was at home, I would definitely go and take it when I remember or if I was outside or out in work, I would make a mental note to take it, when I got home. At the start, I would keep forgetting, it happened maybe a few times a week, but now I've got better. I never took medications really, unless the usual thing, like the flu, antibiotics. This is the longest I've been on medication." (P10) Study 15 "It was so foreign to me to have to take a tablet and to be regimented to take a tablet and all that goes with it. Cognitively I'm not as good or as sharp as I was before I got sick. And I find it's very easy for me to drop the ball and it would be very easy to get that little bit confused." (P7) Study 15 "Sometimes I forget, did I take it today. Sometimes I forget to get my prescriptions from the pharmacy. I have a very bad memory." (P4) Study 15 "There are times I'd forget, if my head is very busy. There is no way I would purposely not take it. I count along the package you see. I'd write on the box even but I still don't because, my memory is not as it used to be." (P3) Study 15 "On Sunday because I'm going to church for communion and I don't have my breakfast or coffee I forget. And I come back after church and I forget." (P4) Study 15 "If you had visitors or if your routine changed or if there was something going on, I might turn round and oh God I didn't take any of my tablets." (P7) Study 15 "I asked myself what do I do everyday of my life? At breakfast, my jar of peanut butter . . . Every morning, it is there." Focus Group 3, Participant F. Study 21
The paradigm model for the category 'The treatment of breast cancer: Stopping the long-term treatment'	
Causal conditions	
Suffering from the treatment severe side-effects Bad quality of life	"I took it and I took it every day and I cried very day and I didn't want to live, wanted to die." Participant 19, age range ≤49, tamoxifen Study 1 "I was just exhausted and it was just getting worse and worse and I realised that I wouldn't be able to work and I couldn't function and I couldn't see myself getting through five years of that." Participant 30, age range 50–64, tamoxifen before stopping with support of health professionals Study 1 "You do get to a point where it just isn't worth it to fight it [staying on AET]" Study 3 "I stopped it in January because I could not take it anymore. . .I could not continue. . .from the first time I took the drug (it was a problem), and far from being decreasing, (. . .) it continued along the Whole journey" (interview 21) Study 5 "Fluid on my lungs with tamoxifen. The doctor stopped my treatment." FGA Study 8 "That's why I stopped—because of the hot flashes." FGB Study 8

	“I put on 20 pounds, I had hair on my chin, it was unbearable As for the libido, there was nothing left at all. I’m young, my husband too, it was not easy! I lost interest in clothes. Suits, heels, I left everything drop, yes, it was an attack on my femininity.” J., aged 39, discontinued the treatment after one year Study 9 “I just stopped everything I was doing. I think I was fixing to go into a depression.” Study 10 “I think once you have cancer you start to think, “Is this mets to the bone, or is this mets somewhere else... or is it a side-effect from the medication”. . . when I take medication, I try not to read the side-effects unless I’m having problems and then I go to the side-effects and say, “Ah, yeah, maybe this is it.” But when I started... in my hips, and it was at night and I was having trouble sleeping, I just decided that... this [anastrozole] wasn’t for me.” Study 11 “I wasn’t prepared to feel the way I felt, I felt so horrible I said to my husband these tablets are making me feel so ill I think I'd rather take the risk with cancer than feel miserable, unhappy, fat.” (P29) Study 15 “I found that I was quite down, and I do have periods where I get quite down. But when I came off it within a couple of months I realised that my mood had picked up, I could feel a kind of, a cloud lift off me. After a month or 2 off it I was suddenly full of energy.” (P12) Study 15 “I just couldn’t survive anymore taking it. My side-effects were so bad I couldn’t work. . .When I stopped and realised the difference, there was no way I was going back on it.” (Bonnie, 61, discontinued) Study 18 “I can’t say that tamoxifen in itself was affecting my moods, but the repercussions of how it [the side-effects] affected my life, again it’s hard to unpick which was having the most effect; was it the drug itself or was it just the repercussions of taking it?” (Bonnie, 61, discontinued) Study 18 “I actually was made to feel as if I was having like a mental breakdown. . .I don’t feel as if I was supported properly.” (Anita, 52, discontinued) Study 18 “I really do think my family thought that I had fallen into a depression and everything just because of the cancer. I think they thought that I thought I was going to die or I just was full of doom and gloom. But it was just out of my control really.” (Anita, 52, discontinued) Study 18 “It scared me what it did to me […] I felt that I was drying up from the inside […] I think my vision went slightly blurry and I felt older with aches and pains […] dry skin and even felt that my teeth were slightly loose.” [P29 nonadherer] Study 19 “Nothing really worked for my [extreme joint pain]. [My doctor] told me to change the timing, taking it in the evening. … We tried all kinds of things. I took Tylenol® … all kinds of stuff … but it didn’t work. … I felt like a 90-year-old woman, so I said, “This is not worth it, and I should stop.” Study 20 “I was walking with crutches and canes for support, but after I stopped taking the tamoxifen, the pain subsided.” Study 20 “I did give it time. I did give it time that I could adjust to it. For two years, I took It. Then It just got so that Instead of getting better, things kept getting worse.” Study 20 “I was at my wit's end [because of side-effects]. I was seeking any and all that could help me. . . . I mean, if I could just explain that it had to almost to the point where l was crippled. I couldn't continue." Study 20 “Well that was my big thing about taking Aromasin If I have to take it for 5 years and my quality of life is so bad, do I want to take it? These are probably the last good 5 years of my life I’m 60 Do I take it and have all these side-effects?” Study 3 “There’s people alive taking hormone medication and there’s people still alive that haven’t taken it. You’re taking a risk with your life too taking it, and sometimes you think ‘well I’d be better off not taking it and I’d live ten years without all that crap” (P19) Study 15 “I didn’t want this awful quality of life, I wanted to be me and if it meant shortening my life, I was willing to take that chance I wanted a better quality of life, than what the tablet was offering me. I’m confident, I didn’t even have to think about it, I made up my mind, this is what I wanted to do I know I will be fine.” (P13) “I don’t want to live in this place where I feel that the medical model has me by the scruff of the neck. I think when you’re diagnosed with cancer, you do become a victim for a while because you are in the clutches of the medical model and that’s where you need to be. But there comes a time when you’re done with your surgery and your radium and then its starts to be the treatment going forward, where you have to take back your choices for quality of life. I went for the best quality I could really for whatever will be remaining for me hopefully. The best commodity I have here now is time so how am I going to use it?” (P27) Study 15 “I stopped taking it three weeks ago and I feel wonderful. I started feeling better after about a week and every week that’s gone past I'm feeling better and better, I feel like me again. I feel great.” (P29) Study 15 “Coming off the tablet has given me back that quality of life. Once I came off the tablet, I felt so well; I felt I was coming back to myself. I really feel well and I have energy. I’ve always had energy, plenty of energy, so I feel I’m back now and I’m happy in myself, because I can do things.” (P13) Study 15 “I know I should be taking them but there's no point because I'm not enjoying life on them. I might as well be dead I thought as feeling like this. Physically, mentally, just totally. I feel great and I'm very happy with my decision because I can't see the point in prolonging life if you're miserable and you have no quality of life, and that’s how I felt on the tablets. I'm getting back to what I used to, what I was like before they put me on the tablets and I feel so much better.” (P29) Study 15 “I chose a lesser time left. I said at my age, does it matter if the cancer comes back one way or another but if I have these few years of, I don’t go gallivanting or that, I like my home and I like being involved in the community, going to the club and that. Coming off the tablet has given me back that quality of life.” (P13) Study 15 “I’m very realistic, I was nearly sixty-one, I had a good life, I have to die of something. I think it’s more to have a life, people don’t say well will this affect my quality of life the medical model wants you to live. They want you to be the success, they want you to be the one they saved, that you’re alive but alive how?” (P27) Study 15 “I thought actually I would rather be myself for however long that is, rather than be miserable for a longer period, and depending on what. . . whether the recurrence might occur or not I just thought well I’ll take that chance.” (Sylvie, 52, discontinued) Study 18

	"I'll have to deal with that if it happens, and the thing is you've no idea, you have no way of knowing if it would've happened anyway. I'm happy enough." (Bonnie, 61, discontinued) Study 18 "I keep thinking OK – you're 73 and it's interesting when you are old what it is […] You want to enjoy the life you have left. You don't want to be on medication that makes you suffer and then die." [P21 nonadherer] Study 19 "I think you need to take life by the horns. You make that decision and take the consequences. I took the decision not to continue because I wanted my normal life again. It is about weighing up what is important to you, not the doctor." [P26 nonadherer] Study 19
No trust in the treatment (negative perception of the treatment)	"I don't take everything they give me." "If it has too many side-effects, I don't take it." FGA Study 8 "I would prefer not to take medication. I don't trust it really, side-effects and damage. I think there is a financial thing in it. Some people are doing research into medication. Not necessarily into people and medication. And when I hear about people taking medication for something and then they have to take medication to balance the medication. And before they know they're on several things. There's this idea that it's better to keep on the medication and we're holding people in this world by just feeding them medication. That would be quite an issue for me." (P2) Study 15 "I'm very anti-drug, just part of who I am so it took a little bit of persuading for me to go on Femara. I don't like drugs. I don't no, well every drug you take there's a side-effect." (P27) Study 15 "research is still under development; they do not know if it helps or not" Study 17 "A friend died from breast cancer, she also took AHT and did not survive anyway". Study 17 "I just don't like taking medication – I never take headache tablets I think in the long run they are all harmful" Study 19 I think the problem with breast cancer is that you're not sick, but it [AET] makes you feel worse than you ever felt. The side-effects are potentially worse than the disease. It's like, 'Why am I doing this?' It's bizarre. (AET non-persistent) Study 23 You want the good stuff that is helping your body, but if you don't know for sure that it's [AET] really helping your body, then why am I taking it? Do I really know that it's benefiting me? And that's probably why I wouldn't take it again. Or, I wouldn't do another five years. Because I haven't seen the benefits yet. (AET persistent) Study 23
Fear from the possible side-effects	"I don't take everything they give me." "If it has too many side-effects, I don't take it." FGA Study 8 "I would prefer not to take medication. I don't trust it really, side-effects and damage. I think there is a financial thing in it. Some people are doing research into medication. Not necessarily into people and medication. And when I hear about people taking medication for something and then they have to take medication to balance the medication. And before they know they're on several things. There's this idea that it's better to keep on the medication and we're holding people in this world by just feeding them medication. That would be quite an issue for me." (P2) Study 15 "I'm very anti-drug, just part of who I am so it took a little bit of persuading for me to go on Femara. I don't like drugs. I don't no, well every drug you take there's a side-effect." (P27) Study 15 "research is still under development; they do not know if it helps or not" Study 17 "A friend died from breast cancer, she also took AHT and did not survive anyway". Study 17 "I just don't like taking medication – I never take headache tablets I think in the long run they are all harmful" Study 19
Being given the choice to stop the treatment by the healthcare provider	"It was based on the doctor having said that the risk was, you know, the benefits were minimal and that if I didn't take it, it would...really, I understood that it wouldn't really matter...and I think I remember reading some- where or hearing somewhere that they were kind of over- prescribing. Would that be right?" (Participant 28, age range ≥65, taking tamoxifen before stopping with support of health professionals) Study 1. "You've got three choices, we could change it to another one, or we could halve it, or we could take you off them altogether and when he said that he went, You could do that, you dinnae need them he says Your kind of cancer wasna bad and I went Right, I'm stopping them." (Participant 29, age range 50–64, taking tamoxifen before stopping with support of HPs) Study 1 "That just made it very easy because he didn't seem particularly bothered about my not taking it...and I was thinking well maybe if we'd had this discussion six months ago, I might have just not taken it." Participant30, age range 50–64, taking tamoxifen before stopping with support of health professionals) Study 1 "It feels good in a way to make your own decisions about your health. I kind of feel, empowered is too strong a word, but I made the decision, I'm not just going along with whatever I'm told to do or whatever is recommended." (P12) Study 15 "You can accept that the medics know a certain amount, they don't know everything. I think to stay on it doesn't seem like a person's responsibility. It seems like its part of the medical system. Whereas if you make a decision you're standing outside that. I do think a lot of people aren't making a conscious decision. They don't know that they can decide. They are going through a process, the doctor said I take this because I have this." (P2) Study 15 "You need to be your own champion and ask the hard questions. I use this loosely and flippantly it's kind of going into battle, battle for yourself. I knew that they wanted me to stay on it, they'd be trying to placate me to stay on it. I was going to tolerate that or was I going to listen to my own body. You're your own best expert." (P27) Study 15

	"I didn't ever try tamoxifen, but [my doctor] told me that she did the number study on how likely . . . taking It would affect . . . that the cancer would come back. It was a very small percentage, so when I couldn't tolerate it well, I didn't. I tried one other one, and when that didn't work, I didn't feel real bad about not taking it." Study 20 "[My oncologist] pulled out my chart … all my history, and we sat down. She said, You have a very low risk of the disease coming back, and you are very sensitive to drugs. [Given the odds], it would be OK if you went off the drug." She said, "I have no problem if you make that decision." So, that's what I did." Study 20
Faith and religion	"The reason I'm not taking drugs anymore is my faith. I very firmly believe that God healed me. I prayed. My church prayed for me. I did exactly what God tells us to do in the Bible and that is to go to Him and ask Him and give Him all the credit for it first, and He did heal me" Study 4
Took it long enough (would not make a difference to continue taking the treatment)	"You do get to a point where it just isn't worth it to fight it [staying on AET]" Study 3 "I have been taking AHT for four years; one year will not make a difference" Study 17 "I'd taken it for 2 years. I'd given it a go. It's been two years since the breast cancer – I feel back to normal now, I don't think it will make much difference now." [P20 nonadherer] Study 19 "I did give it time. I did give it time that I could adjust to it. For two years, I took It. Then It just got so that Instead of getting better, things kept getting worse." Study 20
Lack of physical and emotional support during the treatment	"I actually was made to feel as if I was having like a mental breakdown. . .I don't feel as if I was supported properly." (Anita, 52, discontinued) Study 18 "I just took myself off it so obviously I felt that nobody was interested – I think there needs to be follow-up for hormone therapy." [P31 nonadherer] Study 19 "I didn't ever try tamoxifen, but [my doctor] told me that she did the number study on how likely . . . taking It would affect . . . that the cancer would come back. It was a very small percentage, so when I couldn't tolerate it well, I didn't. I tried one other one, and when that didn't work, I didn't feel real bad about not taking it." Study 20 "I called my doctor and told her that I was going to stop taking Femara", that It was affecting me adversely and that my quality of life was more important." Study
Lack of trust in the healthcare providers and the medical system	"It was based on the doctor having said that the risk was, you know, the benefits were minimal and that if I didn't take it, it would...really, I understood that it wouldn't really matter...and I think I remember reading some- where or hearing somewhere that they were kind of over- prescribing. Would that be right?" (Participant 28, age range ≥65, taking tamoxifen before stopping with support of health professionals) Study 1 "I would prefer not to take medication. I don't trust it really, side-effects and damage. I think there is a financial thing in it. Some people are doing research into medication. Not necessarily into people and medication. And when I hear about people taking medication for something and then they have to take medication to balance the medication. And before they know they're on several things. There's this idea that it's better to keep on the medication and we're holding people in this world by just feeding them medication. That would be quite an issue for me". (P2) Study 15 "You can accept that the medics know a certain amount, they don't know everything. I think to stay on it doesn't seem like a person's responsibility. It seems like its part of the medical system. Whereas if you make a decision you're standing outside that. I do think a lot of people aren't making a conscious decision. They don't know that they can decide. They are going through a process, the doctor said I take this because I have this." (P2) Study 15 "research is still under development; they do not know if it helps or not" Study 17 "I think he said look you are 20% better off on this – you are 20% less likely for it to comeback and I questioned it a bit – and I said I don't want to take it – but he said but you're 40% better off when you take it – but I thought of saying but you didn't say that last time – to be fair well you know these are statistics – statistics can trick you – you can prove anything with statistics – and then when I really thought I really don't want to do this and he went Oh and the statistics went the other way – and he said you're only 10% better off anyway." [P27 nonadherer] Study 19
Actions/interactions	
Communication with healthcare providers and deciding to stop the treatment	"You've got three choices, we could change it to another one, or we could halve it, or we could take you off them altogether and when he said that he went, You could do that, you dinnae need them he says Your kind of cancer wasna bad and I went Right, I'm stopping them." (Participant 29, age range 50–64, taking tamoxifenbefore stopping with support of HPs) Study 1 "Fluid on my lungs with tamoxifen. The doctor stopped my treatment" FGA Study 8 "[My oncologist] pulled out my chart … all my history, and we sat down. She said, "You have a very low risk of the disease coming back, and you are very sensitive to drugs. [Given the odds], it would be OK if you went off the drug." She said, "I have no problem if you make that decision." So, that's what I did." Study 20
Stopping the treatment without communicating with anyone	"The reason I'm not taking drugs anymore is my faith. I very firmly believe that God healed me. I prayed. My church prayed for me. I did exactly what God tells us to do in the Bible and that is to go to Him and ask Him and give Him all the credit for it first, and He did heal me" Study 4 "I don't take everything they give me." "If it has too many side-effects, I don't take it." FGA Study 8 "I don't want to live in this place where I feel that the medical model has me by the scruff of the neck. I think when you're diagnosed with cancer, you do become a victim for a while because you are in the clutches of the medical model and that's where you need to be. But there comes a time when you're done with your surgery and your radium and then its starts to be the treatment going forward, where you have to take back your choices for quality of life. I went for the best quality I could really for whatever will be remaining for me hopefully. The best commodity I have here now is time so how am I going to use it?" (P27) Study 15 "I know I should be taking them but there's no point because I'm not enjoying life on them. I might as well be dead I thought as feeling like this. Physically, mentally, just totally. I feel great and I'm very happy with my decision because I can't see the point in prolonging life if you're miserable and you have no quality of life, and that's how I felt on the tablets. I'm getting back to what I used to, what I was like before they put me on the tablets and I feel so much better." (P29) Study 15

	It feels good in a way to make your own decisions about your health. I kind of feel, empowered is too strong a word, but I made the decision, I'm not just going along with whatever I'm told to do or whatever is recommended. (P12) Study 15 "You need to be your own champion and ask the hard questions. I use this loosely and flippantly it's kind of going into battle, battle for yourself. I knew that they wanted me to stay on it, they'd be trying to placate me to stay on it. I was going to tolerate that or was I going to listen to my own body. You're your own best expert." (P27) Study 15 "I just took myself off it so obviously I felt that nobody was interested – I think there needs to be follow-up for hormone therapy." [P31 nonadherer] Study 19 "I think you need to take life by the horns. You make that decision and take the consequences. I took the decision not to continue because I wanted my normal life again. It is about weighing up what is important to you, not the doctor." [P26 nonadherer] Study 19 "I took myself off the medicine. I went to my primary care physician and told him what I had done. He almost had a heart attack … and I said, "I've had tamoxifen, and I've had breast cancer. I would rather have breast cancer." Study 20
Consequences	
Patients stopping the treatment prematurely	"There's people alive taking hormone medication and there's people still alive that haven't taken it. You're taking a risk with your life too taking it, and sometimes you think 'well I'd be better off not taking it and I'd live ten years without all that crap". (P19) Study 15 "I don't want to live in this place where I feel that the medical model has me by the scruff of the neck. I think when you're diagnosed with cancer, you do become a victim for a while because you are in the clutches of the medical model and that's where you need to be. But there comes a time when you're done with your surgery and your radium and then its starts to be the treatment going forward, where you have to take back your choices for quality of life. I went for the best quality I could really for whatever will be remaining for me hopefully. The best commodity I have here now is time so how am I going to use it?" (P27) Study 15 "I chose a lesser time left. I said at my age, does it matter if the cancer comes back one way or another but if I have these few years of, I don't go gallivanting or that, I like my home and I like being involved in the community, going to the club and that. Coming off the tablet has given me back that quality of life". (P13) Study 15 "I thought actually I would rather be myself for however long that is, rather than be miserable for a longer period, and depending on what. . . whether the recurrence might occur or not I just thought well I'll take that chance." (Sylvie, 52, discontinued) Study 18 "I keep thinking OK – you're 73 and it's interesting when you are old what it is […] You want to enjoy the life you have left. You don't want to be on medication that makes you suffer and then die." [P21 nonadherer] Study 19
Patient accepting that death is not the worst option	"There's people alive taking hormone medication and there's people still alive that haven't taken it. You're taking a risk with your life too taking it, and sometimes you think 'well I'd be better off not taking it and I'd live ten years without all that crap". (P19) Study 15 "I don't want to live in this place where I feel that the medical model has me by the scruff of the neck. I think when you're diagnosed with cancer, you do become a victim for a while because you are in the clutches of the medical model and that's where you need to be. But there comes a time when you're done with your surgery and your radium and then its starts to be the treatment going forward, where you have to take back your choices for quality of life. I went for the best quality I could really for whatever will be remaining for me hopefully. The best commodity I have here now is time so how am I going to use it?" (P27) Study 15 "I chose a lesser time left. I said at my age, does it matter if the cancer comes back one way or another but if I have these few years of, I don't go gallivanting or that, I like my home and I like being involved in the community, going to the club and that. Coming off the tablet has given me back that quality of life". (P13) Study 15 "I thought actually I would rather be myself for however long that is, rather than be miserable for a longer period, and depending on what. . . whether the recurrence might occur or not I just thought well I'll take that chance." (Sylvie, 52, discontinued) Study 18 "I keep thinking OK – you're 73 and it's interesting when you are old what it is […] You want to enjoy the life you have left. You don't want to be on medication that makes you suffer and then die." [P21 nonadherer] Study 19
Better quality of life	"I found that I was quite down, and I do have periods where I get quite down. But when I came off it within a couple of months I realised that my mood had picked up, I could feel a kind of, a cloud lift off me. After a month or 2 off it I was suddenly full of energy." (P12) Study 15 "I stopped taking it three weeks ago and I feel wonderful. I started feeling better after about a week and every week that's gone past I'm feeling better and better, I feel like me again. I feel great." (P29) Study 15 "Coming off the tablet has given me back that quality of life. Once I came off the tablet, I felt so well; I felt I was coming back to myself. I really feel well and I have energy. I've always had energy, plenty of energy, so I feel I'm back now and I'm happy in myself, because I can do things." (P13) Study 15 "I stopped taking them for a couple of weeks while I was on holiday. I'd not taken them before, when I had flu for a week, and realised I felt better not taking them. So I wanted to enjoy my holiday. Get away from the grind of taking them. I just never went back to them. I meant to, it was just no longer I didn't take them" […] [P23 nonadherer] Study 19 You're counting the days and it becomes like you can't wait for the end [of AET]. I don't know what's going to happen. It may come back and I'm going to die anyway. So, I'd rather have a good quality of life while I'm alive and not have side-effects. (AET nonpersistent) Study 23

Regaining control	"I found that I was quite down, and I do have periods where I get quite down. But when I came off it within a couple of months I realised that my mood had picked up, I could feel a kind of, a cloud lift off me. After a month or 2 off it I was suddenly full of energy." (P12) Study 15 "I stopped taking it three weeks ago and I feel wonderful. I started feeling better after about a week and every week that's gone past I'm feeling better and better, I feel like me again. I feel great." (P29) Study 15 "Coming off the tablet has given me back that quality of life. Once I came off the tablet, I felt so well; I felt I was coming back to myself. I really feel well and I have energy. I've always had energy, plenty of energy, so I feel I'm back now and I'm happy in myself, because I can do things." (P13) Study 15 "I stopped taking them for a couple of weeks while I was on holiday. I'd not taken them before, when I had flu for a week, and realised I felt better not taking them. So I wanted to enjoy my holiday. Get away from the grind of taking them. I just never went back to them. I meant to, it was just no longer I didn't take them" […] [P23 nonadherer] Study 19
Having a sense of normalcy	"I found that I was quite down, and I do have periods where I get quite down. But when I came off it within a couple of months I realised that my mood had picked up, I could feel a kind of, a cloud lift off me. After a month or 2 off it I was suddenly full of energy." (P12) Study 15 "I stopped taking it three weeks ago and I feel wonderful. I started feeling better after about a week and every week that's gone past I'm feeling better and better, I feel like me again. I feel great." (P29) Study 15 "Coming off the tablet has given me back that quality of life. Once I came off the tablet, I felt so well; I felt I was coming back to myself. I really feel well and I have energy. I've always had energy, plenty of energy, so I feel I'm back now and I'm happy in myself, because I can do things." (P13) Study 15 "I stopped taking them for a couple of weeks while I was on holiday. I'd not taken them before, when I had flu for a week, and realised I felt better not taking them. So I wanted to enjoy my holiday. Get away from the grind of taking them. I just never went back to them. I meant to, it was just no longer I didn't take them" […] [P23 nonadherer] Study 19
Excluded quotes	
"She [gynecologist] doesn't do anything but her thing. I don't think she would answer my questions. Or even if she did it, you know, would be a brush off kind of thing. She doesn't spend that much time with her patients. I don't think they know about the drugs". Study 3 "They [providers] just go by what they read in a book… I learn more from people who have been through it" Study 3 "How does this information get to the people who don't know?" "Through word of mouth." "There has got to be a better way."[1]"We are supposed to be sharing and communicating with one another- passing information on to one another and that is a good thing. That's the best we can do to get it out there." FGA Study 8 "I would come to group and they would say that being overweight would contribute to high reoccurrence. . . . I gotta take some kind of action. I went to a nutritionist and she worked out a healthy eating plan. My doctor told me to go to the water. I went to water aerobics and I have lost 48 pounds. FGA Study 8 My doctors do not like to hear me talking about Buddhism. Buddha wants human to give up . . . I didn't realize that when I was first diagnosed 6 years ago. I need to talk to my spirit now." Patient 8 Study 2 "Insurance wouldn't pay for a chiropractor. Insurance doesn't pay for physical therapy either" Study 3 "I recommend that the patient does some preliminary study (before the visit). Some patients did not want to leave my office and keep asking when and how often to take the medications repeatedly. They just want to talk to us." Oncologist 4 Study 2 "I'd rather just pick up the phone instead of like putting it all in an email" Study 3 "Many patients told me that the Internet said this and said that. It is a great challenge to teach them to distinguish scientific information from promotions." Oncology nurse 1 Study 2 "Some of my patients felt indebted to their families. They worry about their parents, children, and husbands other than themselves. Actually, their family members are ready to do everything they can to help. Patients should not hesitate to ask for their help, they are always ready to care." Oncology nurse 4 Study 2 "I was kept busy answering questions about the efficacy of all sorts of folk remedies. I can't stop them collecting information from the Internet." Oncology nurse 4 Study 2 "No one but God will discuss death with me. Only God cares for my spirit. . .." Patient 6 Study 2 "Email works for me, but it doesn't work for everybody" Study 3 "I trust Traditional Chinese Medicine, like balance between Yin and Yang, acupuncture, meridian massage . . . I have tried a lot. Those miracles cured by Traditional Chinese Medicine have inspired my spirit. But my doctor was not impressed or interested." (Patient 3) Study 2 "People miss out on a lot of things because they don't know or don't have a pharmacist or social worker that will share ." FGA Study 8 "Almost every patient asks me how long they will live. I always encourage my patients with some miracle cases. Although I am not able to guarantee anything about their life expectancy, I can offer them some encouragement." Oncologist 1 Study 2 "The care-giving burden is generally neglected in China. An optimistic attitude of a caregiver will affect the patients positively." Oncology nurse 3 Study 2 "Family caregivers play a key role in taking care of cancer patients without asking any compensation. If we can reduce the caregivers' stress, cancer patients will receive more effective support." Oncology nurse 4 Study 2 "I met a lot of patients who asked me to explain professional terms endlessly. As you know, doctors in an outpatient clinic of China have very limited time . . . Actually, I don't think a patient need to understand the disease as an expert." Oncologist 3 Study 2 "So I went and looked up, there were lots of forums and things on line, I mean and the truth is that when you read these forums, you really have to be aware that you're mainly going to read stories from people who have had problems." Study 1 Participant 30, age range 50–64,tamoxifen before stopping with support of health professionals	

“I do what the oncologist tells me to” (interview 24) Study 5
“I was just told that I had to take it” (interview 23) Study 5
“. .. if they prescribe them to you, you have to take them by force of circumstances. I am not a doctor so I cannot interfere with their decisions” (interview 14) Study 5
“I accept the situation because cancer is above all things...it is for my own good. . .it is something that fights cancer...” (interview 20) Study 5
"This drug is not a friend, and there is a fear of the unknown... you wonder what you are doing...there is no positive perception, you do not love the drug” (interview 15) Study 5
“Even periodic checks make me feel more at peace” (interview 2) Study 5
“Cancer to me wasn’t cancer to my mom and my sisters. To them cancer was oh Lord, let’s start making arrangements. You know, it wasn’t to me” Study 10
“For some reason I think just the thought of cancer, it really, it, I don’t know, I can’t describe what it does.” Study 10
“We perish with lack of knowledge.” Study 10
“If I was to give any advice to anybody who has been diagnosed with or going through or surviving, it starts with a good prayer life.” Study 10
“And just again, you know, I prayed, I believe in supernatural healing, I do. I believe in medicine, but I believe in supernatural healing from God.” Study 10
“I said Doctor, let me tell you something right now. You sit down. I said the God that I serve is all the psychiatrist that I need.” Study 10
“But, I thank God who is the head of my life that I’m still here. I used to tell myself, you know, I used to ask myself, why me? And I thought about it, why not me?” Study 10
“although religion can be seen to be a facilitator, it also has shown to be a barrier for survivors.” Study 10
“I said we need a support group. We need a support group in [this] county.” Study 10
“If it is I don’t know anything about it [advocacy organization]” Study 10
“You know when I was growing up, it was all hush-hush … you whispered the word ‘cancer’ and now it’s really in our vernacular.” Study 14
I didn’t believe in religion before, but now I believe in Christ under the guidance of my friends. I feel very calm in mind and go to church every week. Now I feel cheerful and like to communicate with others. (P12) study 24
I believe in Buddhism, and I do not pay much attention to this (breast cancer). I didn’t cry or scream as much as anyone else on the day I knew I was sick. I take death lightly, but I am not indifferent. I feel that everything I do in my life will be reversed in my next life. (P14) study 24
What a pity it would be for a woman to have no child. It’s imperfect for women. I will feel very sorry for my husband if I cannot give birth to a child for him, for I don’t want to let him down. (P28) study 24

Appendix 4: Content validity questionnaire

A grounded theory synthesis of the qualitative literature examining adherence to hormone therapy in breast cancer survivorship. Content validity of the pictograms and its representation of the grounded theory models.

This form is used to validate the pictograms and its representation of the categories of the grounded theory models that were developed as part of the grounded theory synthesis.

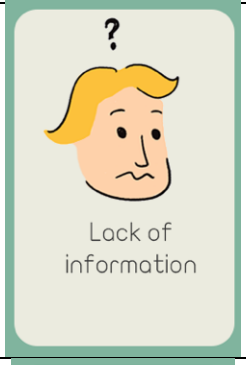
It consists of 76 pictograms and the categories it is supposed to represent. Please answer by choosing one of the options for each pictogram. The question you should answer is "Does the sentence in the first column ('Description') represent the content in the second column ('Pictogram'). Choose one option from (1) strongly agree, (2) agree, (3) disagree, or (4) strongly disagree to answer each question by ticking the box next to your answer. See the example below:

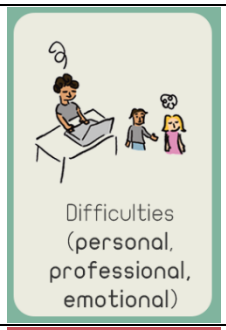
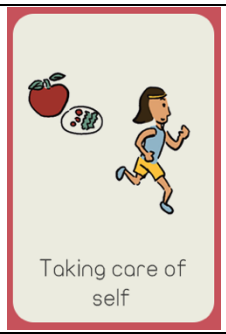
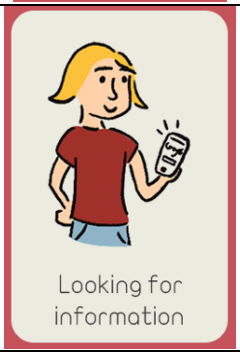
Description	Pictogram	Representation		
Transitioning into a new stage of breast cancer treatment		**1**	**Strongly agree**	√
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	

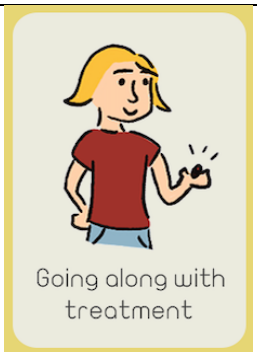
This survey is part of the research being completed by Othman AlOmeir as part of his PhD project. The project is under the supervision of Professor Parastou Donyai. Please return the completed form to the researcher. In case you have any questions please contact the researcher at the following email address: o.k.o.alomeir@pgr.reading.ac.uk.

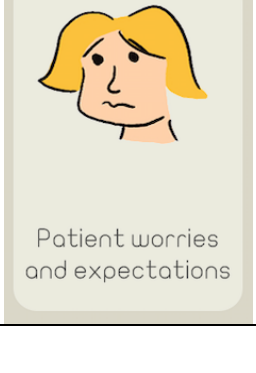
Please start the survey by answering the following questions:

1. What is you gender?	
2. What is your age?	
3. What is your highest level of education?	

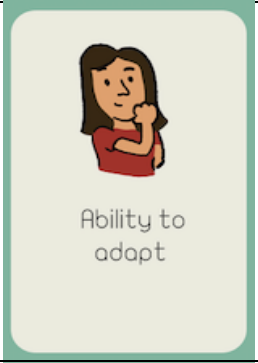
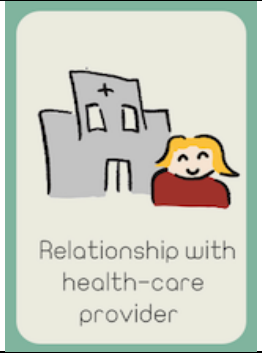
Description	Pictogram	Representation		
Transitioning into a new stage of breast cancer treatment		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
A sense of being overwhelmed by the received information		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Fear of cancer recurrence and fear of possible side-effects of the treatment		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Lack of information and uncertainty about the medication (*necessity, efficacy, safety and mechanism of action*)		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Vulnerability		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	

Experiencing difficulties during the initial stage of the treatment (*personal level, professional level or emotional level*)		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Having a consultation about the medication where it is prescribed		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Patient accepting or deferring the treatment *(dependent on e.g. patient trusting their healthcare provider advice, patient awareness of the necessity of the medication, the level of stability in family and social life, emotional stability and support, patient desire to continue living cancer free, patient co-morbidities, patient need of normalcy)*		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Patients taking care of them-selves		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Patients looking for information else-where (*through specialized websites, specialized forums or from other patients*)		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	

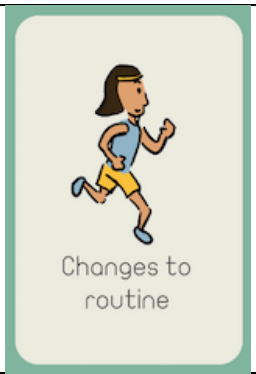
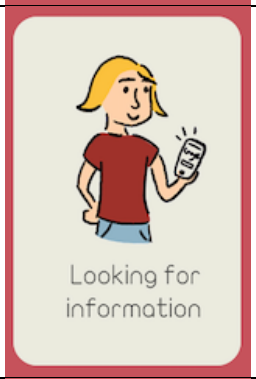
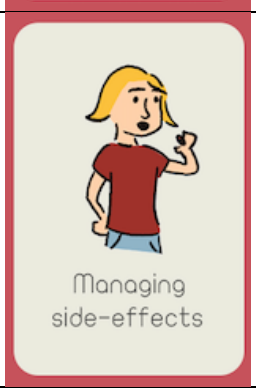
Going along with the hormonal prescription				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Delaying the hormonal treatment				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Transitioning into the long-term treatment phase with ease (*trusting the treatment and finding the necessary support*)				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Having difficulties transitioning into the long-term treatment phase				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Being well informed by receiving the correct information (*not looking for information in the wrong places and correcting the misconceptions about the treatment*)				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	

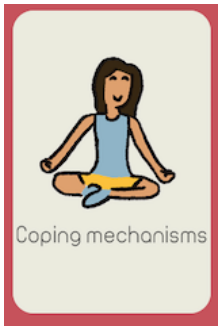
Being wrongly informed about the medication (*side-effects, mechanism of action, efficacy and safety*)			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Less hospital visits (*less communication with healthcare providers*)			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Patient knowledge			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Patient trust in their healthcare provider			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Patient worries and expectations			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	

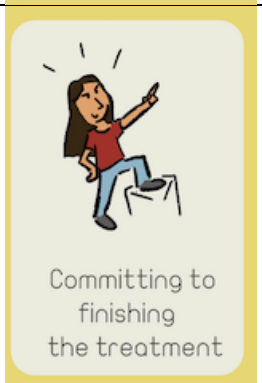
Wanting to continue living cancer free (necessity of the treatment)			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Trust and believe in the treatment and its necessity			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Fear of cancer recurrence (anticipating regret)			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Receiving the correct information about the treatment and side-effects in advance			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Fear of the treatment and its side-effects			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	

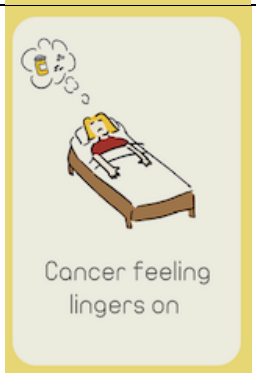
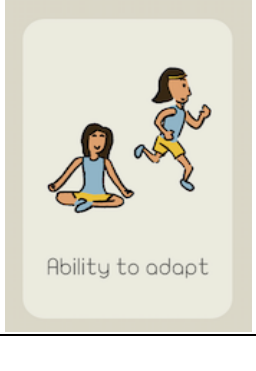
Need of knowledge vs preference of ignorance			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Severity of the side-effects			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Ability to adapt to the treatment and its side-effects			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Ease of access and availability of professional support (specialized physicians, general practitioners, nurses and pharmacists)			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
The relationship with healthcare providers.			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	

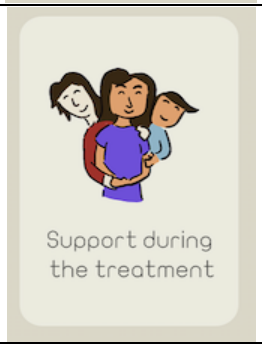
Support from family, friends, co-workers and other patients.				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Owing it to everyone involved				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
The perception of the treatment (positive or negative)				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Continue feeling as a cancer patient throughout the treatment, even though being told that they are cured, and cancer is completely gone.				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Ability to always remember to fill the prescription and take the medication as prescribed				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	

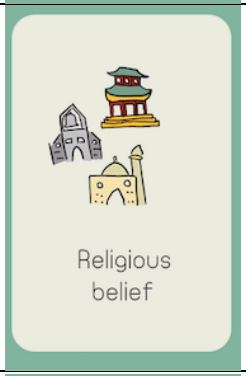
Changes in the patient's usual routine			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Expense of the medications (insurance issues)			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Looking for appropriate support from specialized physicians, general practitioners, nurses, pharmacists, support groups, family and friends			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Looking for other sources of information			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Trying to manage the side-effects			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	

Experimenting with alternative medicine		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Discuss the possibility of changing the hormone therapy medication		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Lifestyle modifications to adapt to the treatment and its side-effects: Quitting work due to lack of energy, moving houses to a smaller one, routine changes (sport, social activities, traveling, housework and sexual intercourse), living healthier (food and activities)		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
The use of coping mechanisms to ease the experience such as: Active coping and self-motivation, seeking support (physically and emotionally), maintaining a positive attitude, meditating, acceptance, humour		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Trying not to forget by making adherence to the treatment a part of the daily routine		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	

Adhering to the treatment				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Having a drug holiday every now and then				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Committing to finishing the whole duration of the treatment				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Suffering from the side-effects of the treatment				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	
Being surprised by the difficulty of the treatment and the severity of the side-effects, thus, finding adherence to be more difficult than originally though				**1**	**Strongly agree**	
				2	**Agree**	
				3	**Disagree**	
				4	**Strongly disagree**	

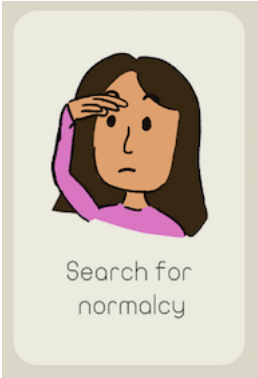
Restriction of social activities			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Side-effects of the treatment, old age and other medications get entangled			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Cancer and being sick keep on lingering throughout the treatment			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Forgetting to take the treatment as prescribed occasionally			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Ability to adapt to the side-effects of the treatment			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	

Knowledge about the treatment		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Support throughout the treatment		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Suffering from the treatment sever side-effects		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Bad quality of life		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
No trust in the treatment (negative perception of the treatment)		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	

Fear from the possible side-effects			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Being given the choice to stop the treatment by the healthcare provider			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Faith and religion			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Took it long enough (would not make a difference to continue taking the treatment)			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	
Lack of physical and emotional support during the treatment			**1**	**Strongly agree**	
			2	**Agree**	
			3	**Disagree**	
			4	**Strongly disagree**	

Lack of trust in the healthcare providers and the medical system		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Communication with healthcare providers and deciding to stop the treatment		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Stopping the treatment without communicating with anyone		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Patients stopping the treatment prematurely		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Patient accepting that death is not the worst option		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	
Better quality of life		**1**	**Strongly agree**	

				2	Agree	
				3	Disagree	
				4	Strongly disagree	
Regaining control				1	Strongly agree	
				2	Agree	
				3	Disagree	
				4	Strongly disagree	
Having a sense of normalcy				1	Strongly agree	
				2	Agree	
				3	Disagree	
				4	Strongly disagree	
Quality of life taking precedence over longevity of life				1	Strongly agree	
				2	Agree	
				3	Disagree	
				4	Strongly disagree	
Patients believes about the treatment necessity				1	Strongly agree	
				2	Agree	
				3	Disagree	
				4	Strongly disagree	

Continuous search of normalcy		**1**	**Strongly agree**	
		2	**Agree**	
		3	**Disagree**	
		4	**Strongly disagree**	

Thank you for taking part and completing the survey. The information you provided will help the project moving forward. If you would like to add anything, please feel free to do so below.

Appendix 5: Data Protection Act

Information Security Policy

Document Control

Issue Status	Author	Description	Date
Version 0.1	Penny Foulkes / Dean Lipscombe	First draft	1st September 2006
Version 0.2	Katherine Vidler/ Dean Lipscombe	Second draft	1st February 2007
Version 0.3	Katherine Vidler	Third draft	1st October 2007
Version 0.4	Katherine Vidler	Fourth draft	7th January 2009
Version 0.5	Natalie Goodson	Fifth draft	6th May 2010

Document Owner – Penny Foulkes

Contents

1 Security Policy

Purpose: Explains what an Information Security Policy should cover and why The Transcription Agency should have one.

This security policy describes:

- The Transcription Agency's requirements for information security.
- The scope of the Information Security Management System (ISMS), including business functions, areas and sites covered.
- The general philosophy towards information security.

1.1 The Requirement

Information exists in many forms and can be printed or written on paper, stored electronically, transmitted by post or electronic means, shown on films and videos or spoken in conversation. This Information Security Policy protects information and the systems which store and process the information, it ensures the confidentiality, integrity, and availability of both vital corporate information and customer information

1.2 Scope

The scope of this policy extends to all activities taking place within The Transcription Agency at its office premises in Hythe. It also covers work being undertaken by home-workers or other situations where work may be being undertaken off-site.

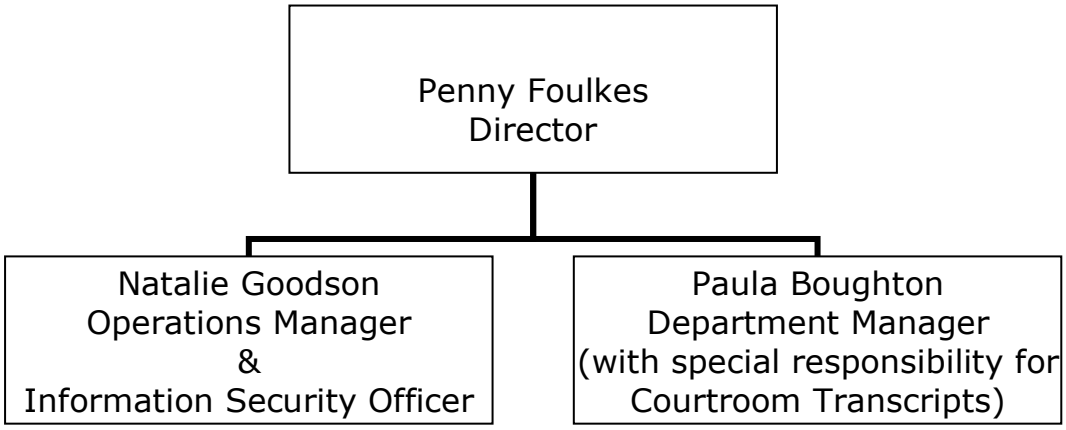
1.3 Philosophy Towards Information Security

The Transcription Agency management support the need for proper safeguards and the effective management of all information processes and is committed to helping protect all persons from identifiable threats, internal or external, deliberate or accidental, ensuring confidentiality, integrity, availability and non-repudiation of information.
Threats may manifest themselves via the unauthorised activities of personnel (due to inadequate awareness training, disinterest, disaffection or coercion), the interception of communications (electronic and manual), physical disruption (including criminal damage and theft) and unauthorised penetration (internal and external).
Any specific policy or procedure relating to the day to day running of the business must be consistent with this security policy.
If an employee encounters a situation that is not specifically mentioned in detail, the Information Security Policy should be a good general guide for actions required and should therefore be the first point of reference.

2 Organisational Security

Purpose: Explains how information security management is organised.

This section describes who is responsible for information security and how it is managed within The Transcription Agency.
The organisational security structure is as follows:



Whilst overall responsibility for the Transcription Agency lies with the Director, Penny Foulkes, everyone in The Transcription Agency has an individual and collective responsibility for information security.

The appointed Information Security Officer is Natalie Goodson, the Deputy Information Security Officer is Paula Boughton. In the first instance, all security related matters should be referred to the Information Security Officer.

The Information Security Officer;

- acts as the focal point for all information security issues.
- seeks to implement organisational structures, policies, procedures and risk management programmes.
- provides guidance on the correct and secure operation of information processing systems and applications.
- quality assures local Information Security Policy documentation.
- seeks to demonstrate an approach to implementing security that is consistent with national and local requirements.
- markets the need for information security.

- provides advice for security education and training.
- co-ordinates investigative and reporting action into all actual and suspected incidents of security significance.
- co-ordinates and advises on the implementation of specific security requirements for new and legacy systems and services.
- establishes and ensures that third party agencies sharing, accessing, storing or processing information and information assets owned by the membership, comply with the defined minimum standards.
- maintains appropriate contacts with other community members, Government departments and regulatory bodies.
-

3 Asset Management

Purpose: Considers information and information processing equipment as valuable assets to be managed and accounted for.

The Transcription Agency is used to maintaining an inventory of physical assets - for example, computers, printers, dictation machinery, etc. but information is also recognised as a vital asset. The value of specific information will depend on factors such as:

- How much it cost to obtain.
- How much it would cost to replace.
- The extent of damage done to The Transcription Agency and client if it was disclosed to the public or a competitor.

An Information Asset Register (IAR) has been created, detailing every information asset within The Transcription Agency. For example:

- Recordings.
- Archived transcriptions.
- Personnel records.
- Databases.
- Templates.
- Contracts.
- Software licences.
- Publicity material.

The Information Asset Register (IAR) also describes:

- Who is responsible for each information asset.
- Any special requirements for confidentiality, integrity or availability.

The value of each asset has been determined to ensure appropriate security is in place.

4 Human Resources

Purpose: Details any personnel issues such as training, responsibilities, vetting procedures, and how staff respond to security incidents.

4.1 Confidentiality

Upon commencement of work at/for The Transcription Agency all persons whether employed, self employed or freelance contractors sign a confidentiality statement which states that all information belongs to the client who supplied it and should not be discussed or shown to any third party. Anyone else with legitimate access to business information or systems is covered.
All persons working for The Transcription Agency who will have access to sensitive information including protectively marked material, e.g. restricted, confidential, and occasionally, secret or top secret, will have completed a Baseline Personnel Security Check which includes confirmation of identity and a Criminal Records Check.

4.2 Security Training

The Information Security Officer is responsible for training all personnel in implementing the Information Security Management System and updating all employees of any changes in policy. New employees are briefed on the need for security and made aware of the Information Security Policy as part of their induction process. In its entirety, the security training reduces the risk of human error and ensures the employees know what their rights and responsibilities are concerning information security.

The security training also deals with rights as well as responsibilities, for example:

- Access to personal files under the Data Protection Act.
- Proper use of equipment as covered by the Computer Misuse Act.

The Transcription Agency views staff training as an important feature of personnel security to ensure the Information Security Management System (ISMS) continues to be effective.

4.3 Feedback

The Transcription Agency actively encourages employees to report security incidents and perceived weaknesses to the Information Security Officer.

5 Physical and Environmental Security

Purpose: Physical aspects of security including protection of equipment and information from physical harm, as well as physical control of access to information and equipment.

The Transcription Agency is committed to ensuring that there is a proper environment for systems, records and employees, all essential for maintaining confidentiality, integrity and availability of information.

5.1 Protection

The protection of information and information systems from the elements is as important as protecting them from unauthorised people. Therefore, the work environment must remain within normal parameters, i.e. free of moisture, excessive humidity and extremes of heat. Working outside these boundaries may result in information system failure or damaged media. Care must also be exercised when transporting media between work locations or to and from the Post Office.
Physical access to the office premises is restricted to authorised personnel and visitors by prior arrangement. Access to the IT and transcription equipment within the office is also similarly restricted to authorised personnel only. This limits the risk of equipment theft or damage by accident or deliberate sabotage.
The main entrance to the office is direct from the High Street and is to remain locked at all times. Visitors to the office are able to use the intercom to identify themselves and have the door opened remotely before proceeding to Reception.

5.2 Maintenance

Maintenance of the physical operating environment in the office is as important as ensuring that paper records are not subject to damage by mould, fire or fading (see above). Supporting equipment such as auxiliary air conditioning plant, burglar alarm or mains services are routinely checked and maintained. If any of these pieces of equipment develop a noticeable fault or start to malfunction, this must be reported to the Information Security Officer as soon as possible for investigation and remedy.

6 Communications and Operations Management

Purpose: Examines correct management and secure operation of information processing facilities during day-to-day activities.

The day-to-day operation of the IT system is fundamental to The Transcription Agency, and as such, security is vital. Keeping the IT and communications systems secure is covered in this section of the policy.

6.1 New or Updated Systems

Any new or updated system being deployed by The Transcription Agency will be checked against acceptance criteria specified during its procurement.

6.2 Anti-abuse Software

All computers being used by The Transcription Agency are required to have;

- Self-updating anti-virus software loaded and set to screen all incoming files.
- A software firewall in place and activated.
- Anti-spam measures in place, e.g. black lists, white lists etc. to filter junk mail.
- Malware detection software (such as Ad-Aware).

In addition, the computers must be set to receive the latest patches released by Microsoft to keep the operating system up to date and secure.

6.3 Network

The Transcription Agency operates a 'peer-to-peer' network based on Windows XP within its office. The connection to the internet is shared across the network and folders on each computer are shared to allow flexibility. All employees using the facility are required to ensure integrity of the system by observing internet access rules and file sharing best practice.

6.4 Internet and Email

In accordance with the Computer Misuse Act 1990, only authorised employees are permitted to use the computer facilities to access the internet for work-related purposes. The email facility is similarly restricted to work matters only. Dispensation to use the facilities for non-work activities either temporarily or at fixed times each day may be given at management discretion.

7 Access Control

Purpose: Control of access to information and systems on the basis of business and security needs.

Access control is about managing direct access to:

- Information.
- Computer applications.
- Operating system facilities.

Effective controls in place ensure that employees have appropriate access to information and applications, and do not abuse it.
User accounts on the office computers are set to 'Limited'. This means users are allowed to run any of the applications as normal but are unable to perform any reconfiguration of the applications or operating system. A separate password protected administrator account is available to make changes. User accounts are periodically reviewed by management to ensure privileges are appropriate and that users do not have access to the applications and data they will never need.
The Transcription Agency believes a balance must be struck depending on:

- Needs of the business.
- Security features provided by the systems.
- Trust in staff.

To achieve this balance, The Transcription Agency management periodically analyse what users require to do their job and the security features each system can provide.

8 Information Systems Acquisition, Development and Maintenance

Purpose: Designing and maintaining systems so that they are secure and maintain information integrity.

In the future it is inevitable that The Transcription Agency will require a new system or need to upgrade the existing system. The specification of any new system will include security requirements that result in effective and workable security features.

This area includes:

- Security requirements analysis and specification.
- Application security.
- Use of cryptography.
- Security of system files.

Any such systems will be scrutinised and tested prior to use to ensure that they work and information remains secure. No new systems or upgrades are to be introduced to the infrastructure without this assurance.

9 Information Security Incident Management

Purpose: Concerned with ensuring information security events and weaknesses are communicated in a way which allows corrective action to be taken.

All employees, contractors and third party users must ensure information security events and weaknesses are reported to the Information Security Officer in order to allow corrective action to be taken. Such incidents must be reported as quickly as possible. Where appropriate to do so, monitoring of incidents and collection of evidence may be required for subsequent investigation and security 'hardening'.

10 Business Continuity Management

Purpose: Concerns the maintenance of essential business activities during adverse conditions, from coping with major disasters to minor, local issues.

The Transcription Agency business relies on its own employees, systems and, to some extent, other organisations. Anything from a burst water main to an earthquake can have a major effect on The Transcription Agency. Furthermore, whilst the office and infrastructure may be untouched, any form of 'incident' outside the premises could lead to access to the office being denied. In such circumstances the Business Continuity Plan will be actioned.
The Business Continuity Plan is managed as a separate document and will be periodically reviewed and tested either for real or as a 'paper exercise'. Its purpose is to ensure that, should access to The Transcription Agency premises or systems be denied for any reason, the business is able to continue by other means, e.g. relocation to Terlingham Manor (Back-up Office), use of back-up equipment etc.

11 Compliance

Purpose: Concerns business compliance with relevant national and international laws, professional standards, and any processes mandated by the Information Security Management System (ISMS).

Every organisation within the United Kingdom is required to comply with UK and EU law.
Within the scope of the Information Security Management System (ISMS), the main laws that affect The Transcription Agency's activities include:

- Health and Safety legislation.
- The Data Protection Act.

- The Computer Misuse Act.
- The Designs, Copyrights and Patents Act; and
- The Human Rights Act.

Compliance with these is a legal requirement and employees should be aware of their principles and impact upon the work of The Transcription Agency.

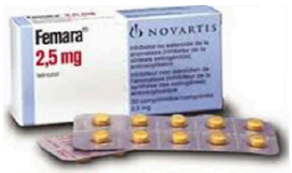
Appendix 6: The recruitment poster

University of Reading

Research participants needed

What are your views and experiences of taking tablets or capsules for breast cancer treatment at home?

I am interested in your views about taking tamoxifen, anastrozole (also known as Arimidex), exemestane (also known as Aromasin), or letrozole (also known as Femara) prescribed for the treatment of breast cancer. I am interested in hearing from women who take their medication exactly as prescribed every day, as well as those who do not. I am completing a PhD in pharmacy at the University of Reading and hope to interview 20 to 30 women in total.



Who? You must be a woman who has had a diagnoses of breast cancer and has received or is receiving a prescription for tamoxifen, anastrozole (also known as Arimidex), exemestane (also known as Aromasin), or letrozole (also known as Femara).

Where? The interview will be conducted at the University of Reading campus or via phone.

Duration? Your participation will consist of one interview estimated to last around an hour.

Will I get paid? You will receive a £20 Amazon voucher for participating in the study and you will be compensated for reasonable travel expenses if applicable.

What if I need more information? As soon as you contact me, I will send you a separate information sheet with further details, for example: how your interview will be used in the study and how I will ensure confidentiality as part of my work.

Please can you help?

If you are interested in joining the study, please contact me and I will send you more information

Researcher details: Othman AlOmeir
Email:
o.k.o.alomeir@pgr.reading.ac.uk
Address:
Reading School of Pharmacy
Harry Nursten building, Whiteknights,
PO Box 226, Reading RG6 6AP, UK
Supervisor details: Prof. Parastou Donyai:
p.donyai@reading.ac.uk

Appendix 7: Information sheet

University of Reading

PhD Pharmacy Student
Mr. Othman AlOmeir
o.k.o.alomeir@pgr.reading.ac.uk

Director, Pharmacy Practice
Prof. Parastou Donyai
PhD, BPharm, PGDPRM(Open), PGCert LTHE
+44 (0)118 378 4704
p.donyai@reading.ac.uk

School of Chemistry, Food & Nutritional Sciences and Pharmacy

Whiteknights
PO Box 266, Reading RG6 6AP, UK
phone +44 (0)118 378 8453
fax +44 (0)118 378 6331

INVESTIGATING ADHERENCE TO ORAL ANTICANCER MEDICATION IN BREAST CANCER SURVIVORSHIP

BACKGROUND

We are interested in studying the views and experiences of women taking medication after a breast cancer diagnosis. We are interested in speaking with women prescribed 'hormonal' treatment including tamoxifen, anastrozole (also known as Arimidex), exemestane (also known as Aromasin), or letrozole (also known as Femara). We want to do this study so that healthcare professionals can understand the range of views, worries and feelings that women express about being asked to take medication for the management of breast cancer.

I would like to invite you to take part in my study, which is about medication taking beliefs in breast cancer treatment, specifically in relation to hormonal treatment.

Why am I conducting this project?

I am conducting this study as a part of my PhD at the University of Reading. I hope this project will allow me to create an understanding about medication adherence in the treatment of breast cancer that I can communicate to healthcare professionals so that they can better support people with their medication in the future and potentially improve people's health outcomes.

What will you have to do if you agree to take part in this project?

If you are interested in taking part in this study, you would spend about an hour talking to me in an interview meeting. If you are interested in this, please contact me through email: o.k.o.alomeir@pgr.reading.ac.uk. I will arrange the meeting at a time and place convenient to both of us at the University of Reading campus. At the start of the interview I will run through this information letter again before asking you to sign the consent form. I aim to audio-record our conversation with your permission. During the interview I will ask questions about your views, opinions and experiences relating to cancer medication and any related topics.

Will you receive any payment for participating in this project?

You will be compensated with a £20 Amazon voucher for giving up your time to participate.

Also, you will be compensated for reasonable travel expenses calculated using the University of Reading expenses rules.

How much time will this project take?

The project consists of one interview that will last around an hour, and depending on where the interview takes place, there will be some travel time.

Will your personal information and participation remain confidential?

If you agree to take part in this project, all your personal information will remain confidential and will never be shared with any other party. Your interview will only be accessible to me and my supervisors. To ensure your confidentiality and anonymity, your name or any identifiable information about you will never be documented against your interview transcript or anywhere else.

What are the advantages of taking part in this project?

You might find the research interesting and a good opportunity to reflect on your own beliefs about medication. Taking part in this study will hopefully help healthcare professionals to better improve patient care in the future.

University of Reading

PhD Pharmacy Student
Mr. Othman AlOmeir
o.k.o.alomeir@pgr.reading.ac.uk

Director, Pharmacy Practice
Prof. Parastou Donyai
PhD, BPharm, PGDPRM(Open), PGCert LTHE
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INVESTIGATING ADHERENCE TO ORAL ANTICANCER MEDICATION IN BREAST CANCER SURVIVORSHIP

What are the disadvantages of taking part in this project?

There are no obvious disadvantages in participating in this project. However, if you feel uncomfortable talking about your medication taking habits and beliefs during the interview, we would ask you to mention this to the researcher and have the interview stopped or paused. Please note, I will not be in a position to answer medication questions or advise on health-related matters.

What will happen to the result of the study?

The study results will be used in my PhD thesis. The outcomes may be presented at conferences and in peer-reviewed journals. If requested, you will be given access to your interview transcript before it is used in the research. You can also have access to the findings of the project after it is completed. The data collected from your interview will be destroyed when the research is completed.

Do you have to take part in this project?

No. Taking part in this study is completely voluntary. You are not obligated to take part if you do not want to. Deciding not to take part in this study does not affect your treatment. If you do not wish to participate in this study you do not have to give a reason and you will not be contacted again. Also, if you take part in an interview, you are free to withdraw from the study, up to three months after the interview; this is because after 3 months, your views and beliefs will have been combined with the views of others and it will not be possible to disentangle your interview specifically.

What if there is a problem?

If you have any complaints about the way you have been dealt with during the study, please contact my research supervisor – see below

What happens now?

If you would like to participate in the study, please contact me by email so that I can answer any questions you have and so that I can arrange to interview you. If you decide not to participate in the study, then no further contact is needed.

Who is organising and funding the research?

This study is being conducted with the University of Reading acting as the academic institution for my PhD. In addition, my research is supported by a full-time scholarship provided by the Saudi Arabian Cultural Bureau.

Who has reviewed the study?

This study has been reviewed and approved by the University of Reading Research Ethics Committee.

Name: Othman AlOmeir
Contact Information
Email: o.k.o.alomeir@pgr.reading.ac.uk
Study mobile number: 01183784704
Supervisor's name: Parastou Donyai
Email: p.donyai@reading.ac.uk
Phone: 0118 378 4704
Address: Reading School of Pharmacy
Harry Nursten building, Whiteknights, PO Box 226, Reading RG6 6AP, UK

Appendix 8: Consent form

University of Reading

PhD Pharmacy Student
Mr. Othman AlOmeir
o.k.o.alomeir@pgr.reading.ac.uk

Director, Pharmacy Practice
Prof. Parastou Donyai
PhD, BPharm, PGDPRM(Open), PGCert LTHE
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INVESTIGATING ADHERENCE TO ORAL ANTICANCER MEDICATION IN BREAST CANCER SURVIVORSHIP

CONSENT FORM

Title of Project: Investigating adherence to oral anticancer medication in breast cancer survivorship
Name of Researcher: Othman AlOmeir

Please initial box

1. I confirm that I have read and understand the information sheet dated 13/11/17 v3 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that while most interviewees will find the discussion interesting and thought-provoking, if I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview. ☐

4. I understand that my participation in this study involves being interviewed by a researcher from University of Reading and the interview will last approximately 60 minutes and will be audio-recorded. I give my permission to the researcher to audio-record the interview by using a digital voice recorder. ☐

5. I understand that my confidentiality as a participant in this study will remain secure and that the transcript of my interview will not contain my name. ☐

6. I have received a copy of this Consent Form and of the accompanying Participant Information Sheet. ☐

7. I give the researcher permission to preserve some or all the data I have provided over the long term and to make the data available in an anonymised form, either openly or subject to appropriate safeguards, so that it can be consulted and re-used by other researchers. ☐

8. I wish to be contacted again about this study (e.g. to be updated on project progress or consulted on any findings or results summaries) ☐
My email address is:……..

University of Reading

School of Chemistry, Food & Nutritional Sciences and Pharmacy

Whiteknights
PO Box 266, Reading RG6 6AP, UK
phone +44 (0)118 378 8453
fax +44 (0)118 378 6331

9. I agree to take part in the above study.

Name……

Signed…….

Date……..

Witnessed by

Name……..

Signature……

Date……

This project has been subject to ethical review, according to the procedures specified by the University Research Ethics Committee, and has been given a favourable ethical opinion for conduct.

Appendix 9: Recruitment email

University of Reading

Circulating e-mail for recruiting participants

Subject heading: **Women breast cancer survivors: can you share your experience of hormone treatment?**

I am conducting a study to better understand medication-taking (medication adherence) in breast cancer survivors and need your help recruiting volunteers for my study.

I am interested in recruiting women diagnosed with breast cancer who have received a prescription for hormone therapy medication [(tamoxifen, anastrozole (also known as Arimidex), exemestane (also known as Aromasin), or letrozole (also known as Femara)] now or in the past. Please find some more information about the study in the attached recruitment poster which you can share with others too. Participants should be able to attend 1 meeting held in the School of Pharmacy lasting around 60 minutes and will be reimbursed £20 with an electronic Amazon voucher for their time.

If you have any more questions please do not hesitate to contact me at o.k.o.alomeir@pgr.reading.ac.uk . I look forward to hearing from you.

Thank you for your time.
Kind regards
Othman

Appendix 10: University of Reading ethics application form

Application Form for UREC Applications

SECTION 1: APPLICATION DETAILS

1.1

Project Title: Investigating adherence to oral anticancer medication in breast cancer survivorship

Date of Submission: 1 Sept 2017 …. Proposed start date: 1 Dec 2017 ….Proposed End Date: 1 July 2019

1.2

Principal Investigator: Dr. Parastou Donyai

Office room number: 1.02 Harry Nursten Building Internal telephone: 0118 378 4704

Email address: p.donyai@reading.ac.uk Alternative contact telephone:
(Please note that an undergraduate or postgraduate student cannot be a named principal investigator for research ethics purposes. The supervisor must be declared as Principal Investigator)

Other applicants

Name: Othman AlOmeir (Student) Department of Pharmacy Email: o.k.o.alomeir@reading.ac.uk
Name: Dr Nicola Stoner (Staff), Cancer Centre, Churchill Hospital Email: nicola.stoner@ouh.nhs.uk
(Visiting Professor at Reading School of Pharmacy)
Name: Dr. Nilesh Patel (Staff) Department of Pharmacy Email: nilesh.patel@reading.ac.uk

….

1.3

Project Submission Declaration

I confirm that to the best of my knowledge I have made known all information relevant to the SCFP Research Ethics Committee and I undertake to inform the Committee of any such information which subsequently becomes available whether before or after the research has begun.

I understand that it is a legal requirement that both staff and students undergo Criminal Records Checks when in a position of trust (i.e. when working with children or vulnerable adults).

I confirm that a list of the names and addresses of the subjects in this project will be compiled and that this, together with a copy of the Consent Form, will be retained

within the School for a minimum of five years after the date that the project is completed.

Signed Dr. Parastou Donyai (Principal Investigator) Date:……

Othman AlOmeir (Student) Date:……

Prof. Nicola Stoner (Other named investigators) Date:……

Dr. Nilesh Patel (Other named investigators) Date:……

1.4

University Research Ethics Committee Applications

Projects expected to require review by the University Research Ethics Committee must be reviewed by a member of the School research ethics committee and the Head of School before submission.

Signed…… (Chair/Deputy Chair of School Committee)
Date:……

Signed…… (Head of Department)
Date:……

Signed…… (SCFP Ethics Administrator)
Date:……

SECTION 2: PROJECT DETAILS

2.1

Please provide a summary of the project in **non-specialist terms** that could be understood by **non-scientist members of the public**, which includes a description of the scientific background to the study (existing knowledge), the scientific questions the project will address and a justification of these. Please note that the description must be sufficient for the committee to take a reasonable view on the likely scientific rigour and value of the project

Patients who are prescribed medication for chronic conditions do not always take their medication as agreed with their doctor. Around half of all patients are thought not to 'adhere' with their medication and this is across many different conditions (1). Patients who are diagnosed with breast cancer and treated in hospital are often prescribed oral medications to take at home in the long term. There is evidence already to show that the problem of non-adherence extends to the long-term management of breast cancer, in the context of 'survivorship'; i.e. from the point of diagnosis to long-term management. However, only one existing qualitative research study has examined the reasons for medication non-adherence in breast cancer treatment (2). It is important to study patients' experiences, voices and opinions if health practitioners are to be able to influence medication-taking behaviours, and improve adherence. In cancer, this would potentially equate to extending the survival period. This project will use grounded theory in order to formally study if, how and why women with breast cancer alter their medication-taking behaviour in relation to hormonal therapy (e.g. tamoxifen) they have been prescribed to take at home. Women participants will be recruited through support groups and other related organisations. Interviews will be conducted face-to-face either in a private room at the university or within the private consultation area of a pharmacy (Day Lewis chain). Interviews will be used to generate an in-depth theory and an explanatory model about women's oral medication-taking practices in breast cancer treatment. Separately, the theoretical domain framework (TDF) will be used to underpin the analysis so that the findings can be used to develop a behaviour-change intervention in the future if possible.

1. Brown MT, Bussell JK. Medication Adherence: WHO Cares? Mayo Clin Proc. 2011 Apr;86(4):304–14.

2. Harrow A, Dryden R, McCowan C, Radley A, Parsons M, Thompson AM, et al. A hard pill to swallow: a qualitative study of women's experiences of adjuvant endocrine therapy for breast cancer. BMJ Open [Internet]. 2014 Jun 12;4(6).

(*This box may be expanded as required – **Word Limit Maximum 250***)

2.2

Procedure

Please describe concisely what the study will involve for your participants and the procedures and methodology to be undertaken (*you may expand this box as required*).

Using purposive sampling, 20-30 adult women who have been prescribed oral hormonal medication for breast cancer treatment will be recruited through recognised support groups or related organisations by liaising with the organisers of groups which agree to work with us. For example, we plan to place posters on noticeboards during support group meetings to alert potential participants to our study and we will ask the support organisations if they would email an electronic copy of the poster to their members. The posters will detail information about the study and provide the PhD student researcher's contact information so anyone interested can make contact and arrange a time for the interview. Interviews will be conducted, audio recorded, transcribed then analysed; first by inductively generating an in-depth grounded theory to explain the medication-taking practices and second by deductively analysing the interviews against an existing psychological framework/theory known as the Theoretical Domain Framework (TDF). The TDF is an integrative framework that has been designed as a vehicle to help theoretic approaches to interventions aimed at behavioural change.

Grounded theory is a qualitative research method used to inductively generate a theory from the data collected during a study. It is a suitable method to use when little is known about the phenomenon under investigation or if there are no grand theories to adequately explain the behaviour that is being studied (1). Combining grounded theory with the TDF will provide another way in which to analyse the data ; i.e. to use a separate theoretical underpinning for the analysis in order to develop a behaviour-change intervention (if deemed possible) and thus bridge the research/theory-practice/impact domains (2). This pluralistic approach (combining grounded theory with an analysis against TDF) will not only provide critical insight for developing an intervention in this area but will also help provide a broader perspective about the phenomenon, increase the confidence in the analysis and help in achieving a rich experience in terms of data analysis (3).

Qualitative Interviews

Before the beginning of an interview, the participant will be asked to sign a consent form. The interviews will then be conducted by the researcher (Othman). All interviews will be conducted in a private room and will be audio-recorded using a digital audio recorder with the participant's consent. The location of the interview is likely to be either a) a private office in the university campus (if the participant is willing to travel to the university) or b) the private consultation room of a Day Lewis pharmacy (if the patient can travel to the local pharmacy and the pharmacist agrees to a mutually convenient time for the use of the room by the researcher). The interviews will be transcribed verbatim on to the Word software before being imported to NVivo. The transcripts will be identified using a

participant code only (non-identifiable code that keeps the personal information about the participant anonymised).

Data analysis

In line with grounded theory methodology, data analysis will take place concurrent with the interviews. This will enable identification of other participant groups that might reasonably contribute to the development of the explanatory model. It will also determine when there is sampling saturation, whereby no more new and significant concepts emerge. The interview transcripts will be subjected to open, axial and selective coding, and concepts developed will be examined for their properties and dimensions. A coding paradigm will then be developed which identify the phenomenon itself, explore the causal conditions, identify the context and the intervening conditions, action and interaction strategies and delineates the consequences for each of the main concepts identified through the coding. Then an explanatory model will be developed to integrate the main concepts into a core category to explain the participants' views and experiences of medication-taking practices in the long-term treatment of breast cancer (4). Afterward, the interviews will be deductively analysed using the TDF. The pluralistic approach will give a diverse range of perspectives and will provide critical insight for developing an intervention in this area.

1. Lyons E, Coyle A. Analysing Qualitative Data in Psychology. SAGE; 2016. 417 p.

2. Allemann SS, Nieuwlaat R, van den Bemt BJF, Hersberger KE, Arnet I. Matching Adherence Interventions to Patient Determinants Using the Theoretical Domains Framework. Front Pharmacol [Internet]. 2016 Nov 14 [cited 2017 Mar 15];7. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC5107738/

3. Frost N. Qualitative Research Methods in Psychology: Combining Core Approaches. McGraw-Hill Education (UK); 2011. 242 p.

4. Charmaz, K. (2014). *Constructing grounded theory* (Second ed.). Thousand Oaks, CA: Sage.

(Note: All questionnaires or interviews should be appended to this application)

2.3

Where will the project take place?

If the project is to take place in Hugh Sinclair Unit of Human Nutrition, projects must be reviewed and approved by the Hugh Sinclair Manager (Dr Michelle Weech, m.weech@reading.ac.uk)

The location of the interviews is going to be either a) a private office in the university campus or b) the private consultation room of a Day Lewis pharmacy. All interviews will be conducted in a private room and will be audio-recorded using a digital audio recorder with consent.

Signed……. (Hugh Sinclair Unit Manager)
Date:…….

2.4

Funding

Is the research supported by funding from a research council or other *external* sources (e.g. charities, business)? Yes

If Yes, please give details:

The student researcher (Othman AlOmeir) is sponsored by the Saudi Arabian Cultural Bureau (SACB) and Shaqra University.

Please note that *all* projects (except those considered as low risk, which would be the decision of the School's internal review committee and require Head of Department approval) require approval from the University Research Ethics Committee.

2.5

Ethical Issues

Could this research lead to any risk of harm or distress to the researcher, participant or immediate others? Please explain why this is necessary and how any risk will be managed.

This qualitative research is being completed with women who have had a diagnosis of breast cancer and have been taking hormonal tablets or capsules at home as part of the long-term management of their condition. As such, the participants are not expected to be in an acute state of illness (and will be excluded if they are too ill to travel for an interview). Nonetheless, the interviews are about medication-taking for the long-term management of breast cancer and, as such, there are ethical issues to consider, described here. The main ones are outlined under the main headings for considering research ethics (as per the British Psychological Society code of human ethics) below;

Respect for the autonomy and dignity of persons: Some people may not want to take part in this study. Therefore, the information sheet makes it very clear that taking part in this research is completely voluntary and that any participant who wishes to, can withdraw their consent at any time before, during and after the beginning of the study without any repercussions. This means that if people agree to participate but then change their minds, their data will be removed from the study and destroyed, and it will be made clear that this would be possible up until the completion of the data analysis (i.e. 3 months from their interview date). In addition, the information sheet will make it clear that during the interviews, the participants have the right to refuse to answer any question that makes them feel uncomfortable or they wish to avoid. Also, unnecessary questions that could cause anxiety will be avoided by thinking through and constructing a semi-structured interview guide. If anyone becomes distressed during the interview then the interview will be stopped or at least paused. We will respect the privacy

of individuals by making sure that they are not personally identifiable: any data collected (e.g. participant quote) will be anonymised so that they cannot be traced back to the individual.

Maximising benefit and minimising harm: we do not anticipate that the participants will be exposed to any harm. The only risk from a study such as this (i.e. talking about medication adherence) is the small risk of 'normalising' unhelpful behaviours, creating self-doubt or 'labelling' individuals (e.g. as non-adherent) or indeed giving an impression that advice will be provided. Here, the researcher will make it very clear in the information sheet and also in the interview itself, that they are acting as a researcher (the researcher is not registered to practise in the UK) trying to understand medication-taking behaviour and not making a judgement about what is the right or wrong behaviour. The language used in the interviews will be sensitive and considered. If a participant does ask for advice, then they will be sign-posted to their practitioner or pharmacist. In addition, the debrief statement will inform participants that the study was about medication-taking and that if they did talk about instances where they have/do not take their medication as prescribed, then this is something they should discuss with their prescriber.

There is also the possibility that participants will feel uncomfortable talking one-to-one with a male researcher (Othman AlOmeir, the PhD student) about a potentially sensitive subject. In order to prevent this, all participants will be invited to attend the interview with a family member / friend with whom they feel comfortable attending the interview; if someone decides to attend on their own, the project supervisor Parastou Donyai will attend the interviews with the student researcher (Othman AlOmeir). Parastou Donyai will attend the first 15 interviews in any case in order to support the training of Othman AlOmeir.

(*this box may be expanded as required*)

2.6

Deception

Will the research involve any element of intentional deception at any stage (i.e. providing false or misleading information about the study, or omitting information)?

[If so, this should be justified. You should also consider including debriefing materials for participants, which outline the nature and the justification of the deception used]

No

2.7

Payment

Will you be paying your participants for their involvement in the study? Yes

If yes, please specify and justify the amount paid

	Participants will be offered a £20 Amazon voucher for participating in the study. This amount was agreed based on the inconvenience subjects might face in giving up their free time to participate in the study. Also, participants will receive compensation for their travel expenses. This amount is believed to be reasonable to achieve the recruitment requirements. Pharmacists who agree to the use of their consultation room will receive a £10 Amazon voucher for each usage of their pharmacy premises. Note: excessive payment may be considered coercive and therefore unethical. Travel expenses need not to be declared.
2.8	**Data protection and confidentiality** What steps will be taken to ensure participant confidentiality? How will the data be stored? Confidentiality will be ensured for all participants involved in the study. All the information gathered in the study will be used for scientific purposes only (i.e. interpretation of transcripts using qualitative methodology, and publication of findings in research papers or through conference presentations or workshops etc.). The participants' written consent will be taken before each interview. The researcher will then use a digital audio-recorder to record the interview. An audio copy of the interviews will be stored on a university password-protected computer in an encrypted file and will only be accessible to the researcher and the supervisors. Then, a transcript of the interviews will be made onto Microsoft word documents with no indication to the subject's name or any information that might identify them. The Transcription Agency may be used in order to help with an initial transcription of the audio files. The Transcription Agency is a preferred supplier of transcription services to the university and has a secure file transfer process as well as certificates to verify data handling in accordance with the Data Protection Act (see Appendix G). The researcher will use non-identifiable codes to keep subjects' identity confidential by checking through the transcripts and ensuring that no identifiable data has been transcribed. Therefore, all hard copies of the interviews will not have any indication about the participant's identity and quotes will not be associated with the participant names or other identifying information. All electronic copies of the audio-recordings will be stored in a university shared drive as an encrypted file only. The electronic copies of the interview will only be accessible to the researcher and the supervisors. After transcription is completed, all digital recordings will be deleted.
2.9	**Consent** Please describe the process by which participants will be informed about the nature of the study and the process by which you will obtain consent All participants will receive an email with the information sheet (description of the study, reasons why the research is being conducted, reasons they have been

chosen to volunteer to participate in the study, nature of the questions they will be asked to answer) and a consent form. The time and location of the interviews will be identified and agreed on in advance. Before any interview the researcher will explain the study to the participant to make sure they fully understand everything in the participant information sheet. Also, the researcher will explain to the participant their right to withdraw from the study at any time and their right to refuse to answer any question that makes them feel uncomfortable. The researcher will make sure to answer all questions asked by the participant prior to the start of the interviews. Written consent will be obtained before the beginning of each interview and a copy of the signed consent form will be given to the participant.

Please note that a copy of consent forms and information letters for all participants must be appended to this application.

2.10

Genotyping

Are you intending to genotype the participants? Which genotypes will be determined?

No

Please note that a copy of all information sheets on the implications of determining the specific genotype(s) to be undertaken must be appended to this application.

SECTION 3: PARTICIPANT DETAILS

3.1

Sample Size

How many participants do you plan to recruit? Please provide a suitable power calculation demonstrating how the sample size has been arrived at or a suitable justification explaining why this is not possible/appropriate for the study.

In line with grounded theory methodology, recruitment will continue until reaching data saturation. Saturation is reached when no new issues, themes, or other participant groups are being identified and the emerged theory can explain all variations in the data. Identifying the exact number of participants before the beginning of the study is difficult as each study is unique. However, based on the other qualitative studies about adherence to oral anticancer medications we anticipate there will be a total of around 20-30 interviews with women diagnosed with breast cancer who are taking oral anticancer medication.

3.2

Will the research involve children or vulnerable adults (e.g. adults with mental health problems or neurological conditions)? No

If yes, how will you ensure these participants fully understand the study and the nature of their involvement in it and freely consent to participate?

(Please append letters and, if relevant, consent forms, for parents, guardians or carers). Please note: information letters must be supplied for all participants wherever possible, including children. Written consent should be obtained from children wherever possible in addition to that required from parents.

3.3

Will your research involve children under the age of 18 years? No
Will your research involve children under the age of 5 years? No

3.4

Will your research involve NHS patients, Clients of Social Services or will GP or NHS databases be used for recruitment purposes? No – this research focusses on survivorship and participants will be recruited through support organisations.

Please note that if your research involves NHS patients or Clients of Social Services your application will have to be reviewed by the University Research Ethics Committee and by an NHS research ethics committee.

3.5

Recruitment
Please describe the recruitment process and append all advertising and letters of recruitment.

Women will be recruited from different support groups that give their written agreement to help with our study identified through the Macmillan cancer support website. Recruitment will likely be through posters (see Appendix F) placed during the support groups meetings or via an electronic copy of the poster emailed by the support organisations to their members. The posters will detail information about the study and provide the researcher's email address and the phone number of a pay-as-you-go mobile phone bought specifically for the purpose of this research. Anyone contacting the researcher will receive an information sheet by email, which will include a description of the study, reasons why the research is being conducted, reasons they have been chosen to participate in the study, nature of the questions they will be asked to answer and so on (Appendix D). If they indicate their interest to take part in the study, the researcher will arrange a meeting with them for the interview. This will be at a time and place mutually convenient to all parties. In the meeting, the researcher will answer any questions the participant may have before asking them to sign the consent form (Appendix C), and proceed to the interview.

Inclusion criteria: Initially, women diagnosed with breast cancer who have been receiving a prescription for an oral hormonal medication for the long-term management of the condition will be selected for the study. This includes the

hormonal drugs tamoxifen and aromatase inhibitors (anastrozole, exemestane, letrozole)

Exclusion criteria: Women in an acute state of illness that prevents them from travelling to conduct the interviews will be excluded. Women unable to provide consent will be excluded. Anyone not prescribed a hormonal oral anticancer agent will be excluded.

List of the local organizations identified through the Macmillan cancer support website that will be approached for their help with recruitment:

Name of the organization	Website	Address and contact information
Three Counties Breast Cancer Support Group		Jackie Wetherell 01344774149 jackiew@btinternet.com
Newbury Breast Care Support Group	www.nbcsg.com	Regency Park Hotel, Bowling Green Road, Thatcham RG18 3RP Maureen Le Du 07795003040 sefton@maureenledu.plus.com
Basingstoke Breast Cancer Self Help Group	www.basingstokebreastcancer.org.uk	The Ark Conference Centre Dinwoodie Drive, Basingstoke, Hampshire RG24 9NN Mrs Angela Bennett 07939 641187 basingstokebreastcancer@gmail.com
Bosom Friends – The Oxfordshire Breast Cancer Support Groups	www.bosomfriends.org.uk	Jan Backhouse and Gilly Edwards 01844 290362 janback@btinternet.com
Brave Front (Alton & District Breast	www.bravefront.co.uk	Stella Royston 07799377008 bravefront@yahoo.co.uk

Cancer Group)		
Breast Friends Aylesbury	• www.breastfriends-aylesbury.org.uk	5 Potash Close, Haddenham, Bucks HP17 8JY Jan Backhouse 01844 290362 07743450833 janback@btinternet.com

Important Notes

1. The Principal Investigator must complete the Checklist in Appendix A to ensure that all the relevant steps and have been taken and all the appropriate documentation has been appended.

2. If you expect that your application will need to be reviewed by the University Research Ethics Committee you must also complete the Form in Appendix B.

3. For template consent forms, please see Appendices C.

Appendix A: Application checklist

This must be completed by an academic staff member (e.g. supervisor)

Please tick to confirm that the following information has been included and is correct.
Indicate (N/A) if not applicable:

Information Sheet

Is on headed notepaper
☒

Includes Investigator's name and email / telephone number
☒

Includes Supervisor's name and email / telephone number
☒

Statement that participation is voluntary
☒

Statement that participants are free to withdraw their co-operation
☒

Reference to the ethical process
☒

Reference to Disclosure ☐ N/A
☒

Reference to confidentiality, storage and disposal of personal information collected
☒

Consent form(s)

☒

Other relevant material

Questionnaires
☒ N/A ☐

Advertisement/leaflets
☒ N/A ☐

Letters
☐ N/A ☒

Other (please specify)
☒ N/A ☐

INTERVIEW SCHEDULE; EMAIL TO SUPPORT ORGANISATIONS

Expected duration of the project 19 (months)

Name (print) Parastou Donyai Signature 

Appendix B: Project Submission Form

Note All sections of this form should be completed. Please continue on separate sheets if necessary.

Principal Investigator: Dr. Parastou Donyai
School: School of Pharmacy
Title of Project: Investigating adherence to oral anticancer medication in breast cancer survivorship
Proposed starting date: December 2017
Brief description of Project:
This project will use grounded theory in order to formally study if, how and why women with breast cancer change their medication-taking behaviour in relation to what they have been prescribed. Interviews with women recruited through support groups will be undertaken. Interviews will be conducted face-to-face either in a private room at the University or within the private consultation area of a Day Lewis pharmacy. Interviews will be used to generate an in-depth theory to explain the medication taking practices. Separately, the theoretical domain framework (TDF) will be used to underpin the analysis so that the findings can be used to develop a behaviour-change intervention in the future if possible.

I confirm that to the best of my knowledge I have made known all information relevant to the SCFP Ethics Committee and I undertake to inform the Committee of any such information which subsequently becomes available whether before or after the research has begun.

I confirm that a list of the names and addresses of the subjects in this project will be compiled and that this, together with a copy of the Consent Form, will be retained

within the School for a minimum of five years after the date that the project is completed.

Signed… .(Investigator) Date 30/8/2017

…….(Head of Department)
Date……

…….(Student)
Date……
(Where applicable)

Checklist

1. This form is signed by my Head of Department ☒

2. The Consent form includes a statement to the effect that the project has been subject to ethical review, according to the procedures specified by the University Research Ethics Committee, and has been allowed to proceed ☒

3. I have made, and explained within this application, arrangements for any confidential material generated by the research to be stored securely within the University and, where appropriate, subsequently disposed of securely. ☒

4. I have made arrangements for expenses to be paid to participants in the research, if any, OR, if not, I have explained why not. ☒

5. Tick EITHER **(a) OR (b) - Head of School to sign if (b) ticked**

   (a) The proposed research does **NOT** involve the taking of blood samples; ☒

   OR

   (b) For anyone whose proximity to the blood samples brings a risk of Hepatitis B, documentary evidence of protection prior to the risk of exposure will be retained by the Head of School. ☐

Signed…….(Head of Department)
Date……

6. Tick **EITHER (a) OR (b)**

(a) The proposed research does **NOT** involve the storage of human tissue, as defined by the Human Tissue Act 2004; ☒

OR

(b) I have explained within the application how the requirements of the Human Tissue Act 2004 will be met. ☐

7. Tick **EITHER (a), (b) OR (c)**

(a) The proposed research will not generate any information about the health of participants; ☒

OR

(b) In the circumstance that any test reveals an abnormal result, I will inform the participant and, with the participant's consent, also inform their GP, providing a copy of those results to each; ☐

OR

(c) I have explained within the application why (b) above is not appropriate. ☐

8. Tick **EITHER (a) OR (b) - Head of School to sign if (b) ticked**

(a) the proposed research does not involve children under the age of 5; ☒

OR

(b) My Head of School has given details of the proposed research to the University's insurance officer, and the research will not proceed until I have confirmation that insurance cover is in place. ☐

Signed…….(Head of Department)
Date……

This form and further relevant information (see Sections 5 (b)-(e) of the Notes for Guidance) should be returned to, Barbara Parr, SCFP Ethics Administrator. You will be notified of the Committee's decision as quickly as possible, and you should not proceed with the project until then.

Appendix 11: University of Reading ethics committee favourable opinion

University of Reading

Coordinator for Quality Assurance in Research
Dr Mike Proven, BSc(Hons), PhD

Academic and Governance Services

Whiteknights House
Whiteknights, PO Box 217
Reading RG6 6AH

phone +44 (0)118 378 7119
fax +44 (0)118 378 8979
email m.j.proven@reading.ac.uk

Dr Parastou Donyai
Reading School of Pharmacy
School of Chemistry Food and Pharmacy
University of Reading
RG6 6AP

26 January 2018

Dear Parastou

UREC 17/51: Investigating adherence to oral anticancer medication in breast cancer survivorship. *Favourable opinion*

Thank you for the response (your email, dated 18 January 2018, refers) addressing the issues raised by the UREC Sub-committee at its November 2017 meeting (*my Provisional Opinion email of 13 November 2017, including attachments refers*). On the basis of these responses, I can confirm that the Chair is pleased to confirm a favourable ethical opinion.

Please note that the Committee will monitor the progress of projects to which it has given favourable ethical opinion approximately one year after such agreement, and then on a regular basis until its completion.

Separately (*and **not** as a condition of approval*), the Committee would like to ask you to consider the recent advice and example statements – from UREC and the University's Research Data Manager, and given via Heads of Schools – to include a statement in the Data Section of the Information Sheet and Consent form that would facilitate the 'downstream' sharing of data. The advice was that the researcher should check that:

"The consent form asks the research participant for permission to preserve some or all of the data they provide over the long term, and to make the data available, in anonymised form if required, either openly or subject to appropriate safeguards, so that they can be consulted and re-used by others, in accordance with the University's Research Data Management Policy."

Two examples of wording which can be used are below, one is anonymised data and the latter is not-anonymised:

> *'I understand that the data collected from me in this study will be preserved and made available in anonymised form, so that they can be consulted and re-used by others.'*
>
> OR

'I understand that the data collected from me in this study will be preserved, and will be made available to other authenticated researchers only if they agree to maintain the confidentiality of the information provided to them.'

Please also find attached Safety Note 59: Incident Reporting in Human Interventional Studies at the University of Reading, to be followed should there be an incident arising from the conduct of this research.

The University Board for Research and Innovation has also asked that recipients of favourable ethical opinions from UREC be reminded of the provisions of the University Code of Good Practice in Research. A copy is attached and further information may be obtained here:

http://www.reading.ac.uk/internal/res/QualityAssuranceInResearch/reas-RSqar.aspx.

Yours sincerely

[redacted]

Dr M J Proven
Coordinator for Quality Assurance in Research (UREC Secretary)
cc: Dr John Wright (Chair); Professor Helen Osborn (Acting Head of School); Mrs Barbara Parr (SREC Secretary);

Appendix 12: Amendment request

Request for amendment

Research Ethics Committee Project No. 17/51: Investigating adherence to oral anticancer medication in breast cancer survivorship. (Favourable opinion dated 26 January 2018).

The project referenced above has been granted approval by the University of Reading Research Ethics Committee. And we would like to ask for a small amendment to the ethics application concerning Othman's project as detailed below.

In essence, the main project methodology remains the same – using purposive sampling to recruit 20-30 adult women who have been prescribed oral hormonal medication for breast cancer treatment. However, instead of recruiting through recognised support groups or related organizations, we will be first recruiting through the University of Reading by circulating an email for recruitment to all staff. Please find the email we would like to circulate for recruitment with this submission.

The rational for this change is to give Othman sufficient experience in interviewing before extending the study through support organizations externally.

We would be grateful to receive your opinion about our submission.

Thank you in advance.

Appendix 13: Amendment favourable opinion

University of Reading

Coordinator for Quality Assurance in Research
Dr Mike Proven, BSc (Hons), PhD

Academic and Governance Services

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email m.j.proven@reading.ac.uk

Dr Parastou Donyai
Reading School of Pharmacy
School of Chemistry Food and Pharmacy
University of Reading
RG6 6AP

16 November 2018

Dear Parastou

UREC 17/51: Investigating adherence to oral anticancer medication in breast cancer survivorship. *Amendment AM01 favourable opinion*

Thank you for your application (email, dated 8 November 2018 and including attachments refers) requesting and detailing amendments to the above project (*addition of cohort recruitment route – University staff*). I can confirm that the UREC Chair has reviewed that request and is happy for the project to continue.

Yours sincerely

[redacted]

Dr M J Proven
Coordinator for Quality Assurance in Research (UREC Secretary)
cc: Dr John Wright (Chair); Professor Rebecca Green (Head of School); Mrs Barbara Parr (SREC Secretary);

Appendix 14: List of codes used, their definitions, the interviews they were used in and the total number of times they were used

Code (concept/category)	Code definition	Interview no. (times used)	Total times used
Ability to find the needed information	Quotes related to participants' ability to find the information they require	Interview 1 (1) Interview 3 (1)	2
Ability to work around the bureaucracy	Quotes related to participants' ability to work out the complexity and bureaucracy of the healthcare system	Interview 1 (2) Interview 3 (1) Interview 6 (1) Interview 7 (1) Interview 8 (1)	6
Accepting the treatment	Quotes related to participants' acceptance of taking the treatment	Interview 1 (3) Interview 2 (1) Interview 3 (1) Interview 4 (3) Interview 12 (1)	9
Accessibility to healthcare providers	Quotes related to participants' accessibility to healthcare providers	Interview 7 (1)	1
Adapting to the treatment	Quotes related to participants' ability to adapt to the treatment and develop adaptive techniques	Interview 3 (1) Interview 4 (2) Interview 5 (2) Interview 6 (1) Interview 7 (2) Interview 9 (2) Interview 11 (1)	11
Adherence	Quotes related to participants' adherence to taking the treatment	Interview 6 (2)	2
Adhering for other people	Quotes related to participants taking the treatment because they feel they owe it to others	Interview 6 (1) Interview 8 (1) Interview 12 (1) Interview 13 (1)	4
Alternative medicine	Quotes related to participants' experimenting with alternative treatments	Interview 1 (2) Interview 2 (1) Interview 3 (1)	17

		Interview 4 (2) Interview 5 (1) Interview 7 (1) Interview 8 (3) Interview 9 (1) Interview 10 (2) Interview 12 (1) Interview 13 (1) Interview 14 (1)	
Anticipating regret	Quotes related to participants' fear of blaming themselves if they do not adhere to the treatment and cancer comes back	Interview 12 (1)	1
Asking for tests and monitoring side-effects	Quotes related to participants having to ask for tests and side-effects monitoring themselves	Interview 12 (2) Interview 14 (1)	3
Bad quality of life	Quotes related to participants experiencing bad quality of life while on the treatment	Interview 14 (4)	4
Being surprised by the side-effects of the treatment	Quotes related to participants being surprised by the side-effects of the treatment	Interview 3 (4) Interview 4 (1) Interview 5 (3) Interview 6 (1) Interview 7 (1) Interview 10 (2)	12
Being well informed	Quotes related to participants being well informed and knowledgeable about the treatment	Interview 2 (1) Interview 14 (2)	3
Believing in the treatment necessity	Quotes related to participants' belief in the treatment's necessity	Interview 1 (1) Interview 2 (1)	2
Chance to ask questions	Quotes related to participants getting a chance to ask questions at the prescription stage	Interview 10 (1) Interview 14 (1)	2
Changes caused by the treatment	Quotes related to the changes participants go through because they are on the treatment	Interview 3 (2) Interview 4 (1) Interview 12 (1)	4
Changes to the healthcare system	Quotes related to the guideline changes as experienced by the participants	Interview 5 (1) Interview 7 (1)	2

Changes to the routine	Quotes related to what happens when there are changes to the participants' routine	Interview 4 (1) Interview 12 (1) Interview 13 (1) Interview 14 (1)	4
Changing the hormonal treatment	Quotes related to participants deciding to change the hormonal treatment from one type to another	Interview 2 (1) Interview 3 (1) Interview 5 (2) Interview 7 (2) Interview 12 (3) Interview 13 (1) Interview 14 (1)	11
Chemo-brain	Quotes related to participants complaining about their memory being affected by the treatment	Interview 4 (1) Interview 12 (1) Interview 13 (2)	4
Committing to taking the treatment exactly as prescribed	Quotes related to participants showing commitment to taking the treatment despite facing difficulties	Interview 2 (1) Interview 5 (1) Interview 6 (1) Interview 8 (1) Interview 10 (1) Interview 14 (1)	6
Concerns about choosing the correct treatment	Quotes related to participants' worries about choosing the correct treatment	Interview 1 (2) Interview 14 (2)	4
Consultation visits experience	Quotes related to participants' experience during consultation visits with their healthcare provider	Interview 14 (1)	1
Continuously looking at the latest information in the field	Quotes related to participants continuously looking for new research, new knowledge and new clinical trials	Interview 1 (1) Interview 2 (1)	2
Continue feeling like a patient	Quotes related to participants continuing to feel like a patient while taking hormone therapy	Interview 2 (2) Interview 3 (2) Interview 5 (1) Interview 7 (1) Interview 8 (1) Interview 9 (2) Interview 10 (1)	10

Continue living cancer free	Quotes related to participants' commitment to taking the treatment to never have cancer again	Interview 9 (1)	1
Continue taking the treatment despite the side-effects	Quotes related to participants powering through the side-effects and continuing the treatment as prescribed	Interview 11 (1) Interview 14 (1)	2
Coping mechanisms	Quotes about participants' techniques for coping with the treatment and its side-effects	Interview 3 (2) Interview 4 (1) Interview 5 (1) Interview 9 (2) Interview 10 (1)	7
Cultural differences	Quotes related to cultural differences and their possible effect on the treatment	Interview 13 (2)	2
Deal with cancer on their own	Quotes related to participants feeling abandoned and left alone to deal with their cancer diagnosis	Interview 6 (1)	1
Deciding to stop the treatment	Quotes related to participants deciding to stop the treatment prematurely	Interview 9 (1) Interview 14 (2)	3
Delaying the start of the treatment	Quotes related to participants deciding to delay treatment before embarking on the hormone therapy journey	Interview 8 (1) Interview 10 (1)	2
Did not feel ill	Quotes related to participants being surprised by the diagnosis and not feeling ill prior to it	Interview 11 (1) Interview 12 (1)	2
Differences between healthcare providers	Quotes related to the differences between healthcare providers' decisions about the type of treatment and prescribed medication	Interview 12 (1)	1
Everyone is experiencing the cancer differently	Quotes related to participants' recognition of the differences between their experience and those of other breast cancer survivors	Interview 3 (1) Interview 4 (1) Interview 7 (2) Interview 10 (1) Interview 11 (1)	5
Expense of the treatment	Quotes related to the expense of the treatment	Interview 1 (1) Interview 5 (2) Interview 13 (1)	4
Experience with health insurance	Quotes related to participants' experience with health insurance	Interview 4 (2)	2
Experience with the diagnosis	Quotes related to participants' experience during the breast cancer diagnosis and how it affected them	Interview 12 (1)	1

Experience with the treatment	Quotes related to participants' general experience of the treatment in their everyday lives	Interview 1 (1) Interview 2 (2) Interview 3 (1) Interview 4 (2) Interview 8 (2) Interview 12 (1)	9
Experiencing severe side-effects	Quotes related to participants experiencing severe side-effects from hormone therapy	Interview 3 (2) Interview 5 (2) Interview 6 (1) Interview 13 (1) Interview 14 (4)	10
Experiencing difficulties during the initial stage of the treatment	Quotes related to participants experiencing difficulties during the initial stage of the treatment	Interview 9 (2) Interview 14 (2)	4
Experiencing no side-effects	Quotes related to participants experiencing no side-effects while taking the treatment	Interview 8 (1)	1
Fear from the side-effects of other treatments	Quotes related to participants expressing their fear of suffering from the side-effects of other medications being taken while on the treatment	Interview 3 (1) Interview 13 (1)	2
Fear of becoming a burden	Quotes related to participants' fear of becoming a burden on their family or the medical system	Interview 6 (1)	1
Fear of cancer coming back	Quotes related to participants expressing their fear of cancer recurrence	Interview 3 (4) Interview 4 (5) Interview 5 (1) Interview 6 (6) Interview 7 (2) Interview 8 (2) Interview 9 (3) Interview 10 (1) Interview 11 (2) Interview 12 (2) Interview 13 (2)	30
Fear of losing the protective properties of the treatment	Quotes related to participants' fear of stopping the hormonal treatment after reaching the end of the course and losing the protective properties it provides	Interview 1 (2) Interview 2 (6) Interview 3 (1)	13

		Interview 5 (1) Interview 9 (1) Interview 13 (2)	
Fear of the treatment and its possible side-effects	Quotes related to participants' fear of the possible side-effects of the treatment	Interview 1 (2) Interview 4 (2) Interview 6 (2) Interview 7 (1) Interview 8 (4) Interview 9 (3) Interview 11 (1)	15
Feelings after stopping the treatment	Quotes related to how participants felt after deciding to stop the treatment	Interview 14 (2)	2
Filling in the prescription	Quotes related to participants' experience of filling in the prescription throughout the treatment	Interview 1 (2) Interview 2 (2) Interview 3 (2) Interview 4 (3) Interview 5 (2) Interview 6 (2) Interview 7 (2) Interview 8 (1) Interview 9 (1) Interview 10 (1) Interview 11 (1) Interview 12 (1) Interview 14 (1)	21
Forgetting to take it once is no big deal	Quotes related to how participants felt if they forgot to take the treatment	Interview 4 (1) Interview 6 (1) Interview 7 (1) Interview 9 (1) Interview 12 (1) Interview 14 (2)	7
Forgetting to take the treatment as prescribed	Quotes related to participants forgetting to take the treatment as prescribed	Interview 3 (2) Interview 4 (3) Interview 6 (1)	17

		Interview 7 (1) Interview 8 (2) Interview 9 (3) Interview 11 (1) Interview 12 (2) Interview 13 (1) Interview 14 (1)	
Given the choice to stop	Quotes related to participants being given the choice to stop the treatment by their healthcare provider	Interview 5 (1) Interview 9 (1) Interview 11 (1) Interview 13 (1)	4
Good cooperation between the different health sectors	Quotes related to participants' good experiences in regard to the cooperation between different health sectors	Interview 4 (1) Interview 10 (1)	2
Googling	Quotes related to participants' use of internet searching to find information	Interview 7 (1) Interview 11 (2) Interview 12 (1) Interview 13 (1)	5
Having other priorities (other aspects of life interfering with the treatment)	Quotes related to participants having other priorities that sometimes take precedence over the treatment	Interview 3 (1) Interview 4 (6) Interview 8 (2) Interview 9 (1)	10
Help from family and friends during the prescription	Quotes related to participants receiving help from their family and/or friends during the prescription stage of the treatment	Interview 1 (1) Interview 12 (1)	2
Hobson's choice	Quotes related to the core category "Hobson's choice" and whether or not participants felt they had a real choice in regard to taking the treatment	Interview 5 (2) Interview 6 (4) Interview 8 (2) Interview 10 (1) Interview 11 (3) Interview 12 (1) Interview 13 (2)	15
Hormone therapy is not a big deal	Quotes related to participants feeling as if taking a hormonal treatment pill daily is not a significant inconvenience	Interview 2 (1)	1

Hormone therapy vs. Chemotherapy	Quotes related to participants making a comparison between hormone therapy and chemotherapy	Interview 5 (1)	1
Inability to ask for help	Quotes related to participants expressing an inability to ask for help while on the treatment	Interview 3 (1)	1
Inaccessibility to healthcare providers	Quotes related to participants complaining about not having access to healthcare providers	Interview 7 (1)	1
Keeping a journal	Quotes related to participants keeping a journal to record all breast cancer-related matters	Interview 10 (1) Interview 12 (1)	2
Keeping it a secret (cancer: taboo or acceptable)	Quotes related to participants wanting to keep their cancer diagnosis a secret due to social pressure	Interview 14 (3) Interview 5 (1)	4
Knowledge about the treatment	Quotes related to participants' pre-existing knowledge about the treatment	Interview 1 (4) Interview 2 (1) Interview 4 (5) Interview 5 (2) Interview 6 (2) Interview 7 (3)	17
Lack of compassion from healthcare providers	Quotes related to participants complaining about a lack of compassion from some healthcare providers during the treatment	Interview 10 (2) Interview 13 (1)	3
Lack of cooperation and communication between the various healthcare providers	Quotes related to participants' bad experiences in regard to the cooperation between various health sectors	Interview 3 (4) Interview 6 (1) Interview 7 (4) Interview 9 (1)	10
Lack of empathy from other people	Quotes related to participants complaining of a lack of empathy on the part of other people and how they resent them meddling in their affairs	Interview 3 (3)	3
Lack of follow-up during the treatment	Quotes related to participants' complaints about the lack of follow-up while they are still on the treatment	Interview 1 (1) Interview 3 (4) Interview 13 (1)	6
Lack of information	Quotes related to participants showing uncertainty and/or lack of knowledge about the treatment	Interview 2 (3) Interview 3 (6) Interview 4 (1) Interview 6 (2) Interview 13 (2) Interview 14 (1)	15

Lack of knowledge about the availability of support	Quotes related to participants complaining that they did not know about the availability of various forms of support	Interview 9 (4)	4
Lack of support during the treatment	Quotes related to participants complaining about a lack of support during the treatment	Interview 1 (5) Interview 3 (6) Interview 6 (3) Interview 7 (3) Interview 8 (1) Interview 9 (1) Interview 12 (3) Interview 14 (1)	23
Lack of time during the appointment visit	Quotes related to the lack of time spent on participants during follow-up visits and their feelings about it	Interview 7 (1) Interview 14 (1)	2
Lack of time during the prescription visit	Quotes related to the prescription visit and whether or not participants were given enough time with their healthcare provider	Interview 8 (1)	1
Lack of trust in healthcare provider	Quotes related to participants expressing a lack of trust in their healthcare provider	Interview 1 (1) Interview 4 (1) Interview 8 (2)	
Lack of understanding of the provided information	Quotes related to participants' inability to understand the provided information	Interview 12 (1) Interview 13 (1)	2
Fewer hospital visits	Quotes related to the fact that participants have less contact with hospitals and healthcare providers while on hormone therapy	Interview 1 (2) Interview 9 (1)	3
Lifestyle changes	Quotes related to lifestyle changes participants need to make to better adjust to the hormone therapy	Interview 1 (1) Interview 2 (3) Interview 3 (3) Interview 4 (5) Interview 5 (2) Interview 6 (1) Interview 7 (3) Interview 9 (1) Interview 10 (4) Interview 11 (1) Interview 12 (2) Interview 13 (1)	30

		Interview 14 (3)	
Limit of healthcare providers' knowledge	Quotes related to participants' complaints about healthcare providers' lack of knowledge about the treatment and its side-effects	Interview 3 (1) Interview 7 (1) Interview 12 (2) Interview 13 (5) Interview 14 (5)	14
Living with the side-effects	Quotes related to participants adjusting to and living with the treatment's side-effects	Interview 4 (4) Interview 6 (1) Interview 7 (1) Interview 9 (1) Interview 10 (1)	8
Looking for hope and encouragement	Quotes related to participants' occasional need for expressions of hope and encouragement from their healthcare providers	Interview 10 (1)	
Losing control while on the treatment	Quotes related to participants complaining about losing control over their life due to breast cancer and the treatment	Interview 3 (1)	1
Making a decision without getting time to think	Quotes related to participants feeling they had to make a decision on whether or not take to the treatment having had chance to think it over	Interview 1 (1)	1
Making sure the treatment is working	Quotes related to participants wishing there was a chance to be sure the treatment is working	Interview 12 (1) Interview 14 (3)	4
Managing the side-effects of the treatment	Quotes related to what participants did to manage the side-effects of the treatment	Interview 2 (1) Interview 3 (2) Interview 4 (1) Interview 5 (1) Interview 6 (2) Interview 7 (3) Interview 9 (3) Interview 10 (1) Interview 12 (2) Interview 14 (1)	17
Menopausal or not menopausal	Quotes related to the uncertainty some participants feel while deciding what treatment they should go for, due to the fact that they don't know whether they are menopausal or not	Interview 1 (1) Interview 5 (1)	2

Missing one is no big deal	Quotes related to participants' nonchalant behaviour in regard to missing a dose of the treatment	Interview 3 (1) Interview 5 (1)	2
Monitoring bone density	Quotes related to participants having to monitor bone density during the treatment	Interview 1 (1) Interview 3 (1) Interview 4 (1) Interview 7 (1) Interview 9 (1)	
Prioritizing other people's issues (motherhood taking precedence over the condition)	Quotes related to participants prioritizing motherhood over themselves	Interview 5 (1) Interview 6 (1)	2
No chance to ask questions	Quotes related to participants' complaints about the lack of opportunity to ask question during their appointments	Interview 6 (1)	1
Not being told about reaching the end of the line	Quotes related to participants not being told they have reached the end of the treatment and having to ask about it themselves	Interview 1 (3)	3
Not being told the medication is free	Quotes related to the fact that some participants did not know their treatment was free of charge	Interview 4 (2)	2
Not surprised by the side-effects	Quotes related to side-effects matching participants' expectations	Interview 9 (1)	1
Only peers (those taking the treatment) would understand	Quotes related to participants feeling that only fellow breast cancer survivors could understand what they are going through	Interview 3 (1) Interview 4 (1) Interview 6 (1) Interview 7 (1) Interview 9 (2) Interview 10 (2)	8
Organizing future appointments	Quotes related to hospitals organizing participants' future appointments	Interview 5 (2)	2
Over-prescribing	Quotes related to participants complaining about healthcare providers overprescribing medications and their fear of same	Interview 3 (1) Interview 4 (1)	2
Part of the routine	Quotes related to participants making their taking of medication part of their daily routine to make sure they do not forget	Interview 4 (1) Interview 5 (1) Interview 6 (1) Interview 7 (1) Interview 10 (1)	8

		Interview 11 (1) Interview 12 (1) Interview 14 (1)	
Payment for the treatment	Quotes related to participants talking about not having to pay for the treatment	Interview 3 (3) Interview 4 (3) Interview 6 (1) Interview 14 (1)	8
Perception of the treatment	Quotes related to participants' perception of the treatment and whether it changed or stayed the same throughout	Interview 1 (2) Interview 2 (2) Interview 3 (2) Interview 4 (1) Interview 7 (1) Interview 8 (1) Interview 9 (1) Interview 10 (3) Interview 14 (2)	15
Pessimism vs. optimism	Quotes related to participants thinking positively and seeing the good in a bad situation	Interview 11 (1)	1
Pharmacist's role in the healthcare system	Quotes related participants' descriptions of the pharmacist's role during the treatment	Interview 7 (2) Interview 14 (2)	4
Positivity vs. reality	Quotes about participants' state of mind and the differences between staying positive and being real	Interview 7 (1) Interview 10 (1) Interview 12 (1)	3
Preference for knowledge vs. preference for ignorance	Quotes related to participants' preference when it comes to wanting information in advance or not unless/until it becomes necessary	Interview 1 (2) Interview 2 (1) Interview 4 (1) Interview 5 (1) Interview 6 (1) Interview 8 (2) Interview 10 (2) Interview 12 (2)	12
Quality of life over longevity	Quotes related to participants' prioritizing of quality of life over longevity	Interview 14 (1)	1

Reaching the end of the line	Quotes related to participants' reaching the end of the hormonal treatment	Interview 1 (3) Interview 2 (2) Interview 3 (2) Interview 4 (3) Interview 5 (3) Interview 6 (2) Interview 7 (3) Interview 8 (1) Interview 9 (1) Interview 10 (2) Interview 11 (3) Interview 12 (1) Interview 13 (3) Interview 14 (2)	31
Reasons to start the treatment	Quotes related to participants' reasons for starting the treatment	Interview 10 (1) Interview 12 (1) Interview 14 (1)	3
Reasons to do this research	Quotes related to the importance of conducting a study to understand breast cancer survivors' experiences with hormone therapy	Interview 3 (1) Interview 13 (1) Interview 14 (3)	5
Reassessment after five years	Quotes related to participants reassessing their options with hormone therapy after reaching the five-year mark	Interview 6 (2) Interview 9 (1) Interview 12 (2) Interview 13 (1) Interview 14 (2)	8
Receiving information gradually	Quotes related to participant receiving information gradually instead of being bombarded with it all at once	Interview 10 (2)	2
Receiving too much information during the first visit	Quotes related to participants being bombarded with a lot of information at the start of the treatment	Interview 1 (1) Interview 2 (2)	3
Receiving reminders to fill in the prescription	Quotes related to participants receiving reminders from their pharmacy to fill in the prescription	Interview 7 (1)	1
Receiving enough information	Quotes related to participants receiving enough information to make informed decisions	Interview 7 (1) Interview 10 (2)	3

Receiving too much information	Quotes related to participants being bombarded with information throughout the treatment	Interview 1 (1) Interview 2 (1) Interview 3 (1) Interview 8 (1) Interview 9 (1) Interview 10 (1) Interview 14 (1)	7
Regaining normalcy	Quotes related to participants' desire to feel normal again	Interview 1 (1) Interview 4 (2) Interview 7 (1) Interview 9 (1) Interview 13 (1) Interview 14 (1)	7
Relationship with healthcare provider	Quotes related to participants having a good relationship with their healthcare provider and how it affected their treatment	Interview 2 (4) Interview 3 (2) Interview 4 (1) Interview 5 (2) Interview 6 (2) Interview 7 (4) Interview 9 (1) Interview 10 (1) Interview 11 (1) Interview 12 (2)	20
Relationship with partner	Quotes related to participant' relationship with their partner while on hormone therapy	Interview 3 (1) Interview 9 (1)	2
Remembering to take the treatment daily	Quotes related to participants remembering to take the treatment every day	Interview 1 (1) Interview 2 (1) Interview 5 (1) Interview 9 (1) Interview 11 (1) Interview 12 (1)	6
Restriction of social activities	Quotes related to the treatment and its side-effects restricting participants' social lives	Interview 2 (1) Interview 3 (2)	7

		Interview 4 (1) Interview 6 (1) Interview 9 (1) Interview 10 (1)	
Self-image on the treatment	Quotes related to participants' views of how the treatment and its side-effects affected their self-image	Interview 9 (3) Interview 12 (2)	5
Side-effects get entangled	Quotes related to the side-effects of hormone therapy getting mixed up with the side-effects of other treatments and with the effect of aging	Interview 1 (3) Interview 4 (1) Interview 6 (1) Interview 7 (4) Interview 9 (3) Interview 11 (1) Interview 12 (1)	14
Side-effects of the treatment	Quotes related to the side-effects of the treatment	Interview 1 (3) Interview 2 (2) Interview 3 (3) Interview 4 (3) Interview 5 (1) Interview 6 (1) Interview 7 (6) Interview 9 (7) Interview 10 (2) Interview 12 (2) Interview 14 (3)	33
Sources of information (finding the needed information)	Quotes related to other sources of information mentioned by participants in their interviews	Interview 1 (3) Interview 2 (4) Interview 3 (3) Interview 4 (4) Interview 5 (2) Interview 6 (3) Interview 7 (4) Interview 8 (2) Interview 9 (2)	33

		Interview 10 (1) Interview 11 (1) Interview 12 (2) Interview 13 (1) Interview 14 (1)	
Stopping the treatment prematurely	Quotes related to participant deciding to stop the treatment prematurely	Interview 1 (1) Interview 9 (2) Interview 11 (2) Interview 13 (5) Interview 14 (1)	11
Support at work and from co-workers	Quotes related to the support participants got from their employer and co-workers	Interview 4 (1) Interview 14 (1)	2
Support during the treatment	Quotes related to the professional support participants received during their treatment	Interview 2 (5) Interview 5 (1) Interview 6 (2) Interview 7 (4) Interview 8 (2) Interview 10 (3) Interview 11 (1) Interview 13 (1) Interview 14 (2)	21
Support from family and friends	Quotes related to the support participants received from family and friends while on hormone treatment	Interview 1 (1) Interview 2 (2) Interview 3 (3) Interview 4 (6) Interview 5 (2) Interview 6 (2) Interview 8 (1) Interview 9 (2) Interview 10 (1) Interview 12 (4) Interview 13 (1) Interview 14 (3)	28

Support groups	Quotes related to participants' views and opinions about support groups	Interview 6 (1) Interview 7 (1) Interview 8 (1) Interview 9 (1) Interview 10 (1) Interview 11 (1) Interview 12 (2) Interview 13 (2) Interview 14 (2)	12
Sympathy does not help	Quotes related to participants' preference for professionalism over sympathy	Interview 9 (3)	3
Taking a drug holiday	Quotes related to participants' views and opinions about drug holidays	Interview 1 (1) Interview 3 (2) Interview 4 (2) Interview 6 (1) Interview 7 (2) Interview 8 (1) Interview 9 (1) Interview 10 (1) Interview 13 (2) Interview 14 (1)	14
Taking one more pill is not a big deal	Quotes related to participants' views about how simple they found taking hormone therapy	Interview 8 (1)	1
Taking the treatment at night instead of morning	Quotes related to participant changing the time they take the treatment to reduce the side-effects	Interview 9 (1)	1
The benefits of taking the treatment for ten years	Quotes related to the benefits of taking the treatment for ten years, as compared with the original five	Interview 3 (1) Interview 8 (1)	2
The dilemma of taking the treatment or not taking it	Quotes related to the core "horned dilemma" category	Interview 2 (1) Interview 3 (2) Interview 4 (8) Interview 6 (4) Interview 9 (1) Interview 11 (5) Interview 13 (2)	24

		Interview 14 (1)	
The information is overwhelming	Quotes related to participants being overwhelmed by the amount of information they receive	Interview 6 (1) Interview 12 (1)	2
The need for more professional support	Quotes related to participants' need for more professional support throughout the treatment	Interview 3 (3) Interview 6 (5) Interview 7 (1) Interview 8 (1) Interview 14 (1)	11
The need for more information	Quotes related to participants' need for more information throughout the treatment	Interview 2 (1) Interview 3 (1) Interview 6 (4)	6
The internet experience	Quotes related to participants' experiences of surfing the web and breast cancer-related forums in particular	Interview 7 (2) Interview 8 (2) Interview 12 (2)	6
The prescription visit experience	Quotes related to participants' experience during their prescription visits	Interview 1 (1) Interview 3 (1) Interview 6 (1) Interview 7 (2) Interview 8 (1) Interview 9 (2) Interview 10 (1) Interview 11 (1) Interview 12 (2) Interview 13 (1)	13
The transition into a new stage of the treatment	Quotes related to participants identifying the transition to a new stage of the treatment	Interview 1 (2) Interview 2 (2) Interview 3 (2) Interview 5 (1) Interview 8 (1) Interview 12 (1)	9
Treatment follow-up	Quotes related to participants' experiences during the follow-up visit	Interview 1 (3) Interview 4 (1) Interview 12 (1)	6

		Interview 13 (1)	
Trust in the healthcare provider	Quotes related to participants' trust in their healthcare provider	Interview 5 (2) Interview 6 (1) Interview 9 (1) Interview 10 (4) Interview 11 (2) Interview 12 (2) Interview 14 (1)	13
Trust in the treatment	Quotes related to participants' trust in the treatment and its ability to prevent cancer recurrence	Interview 1 (1) Interview 2 (3) Interview 4 (1) Interview 5 (2) Interview 6 (2) Interview 7 (1) Interview 9 (1) Interview 10 (2) Interview 11 (1)	14
Trying a different brand	Quotes related to participants changing their brand of medication in hopes of reducing side-effects	Interview 7 (1) Interview 12 (4) Interview 13 (1) Interview 14 (1)	7
Vulnerability	Quotes related to participants feeling vulnerable	Interview 1 (1) Interview 2 (1) Interview 4 (1) Interview 5 (1) Interview 7 (2)	6
Worries and expectations	Quotes related to participants' worries and expectations when starting the treatment	Interview 10 (1) Interview 11 (1)	2