# A pluralistic qualitative study of the experience of taking medication for secondary prevention of acute myocardial infarction

A thesis submitted for the degree of Doctor of Philosophy (PhD) in Pharmacy

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And with each thought a pang came to his heart that had shattered, a pang of regret that he could not go on like other men having new extraordinary experiences day after day. Most extraordinary was that his heart had gone on beating thirty-five years without once stopping to complain about the thankless, endless task.

Herbert Clyde Lewis

*Gentleman Overboard, 1937*

(Herbert Clyde Lewis gained little recognition for his writing during his lifetime, was bankrupt and found dead in his hotel room in 1950. The cause of his death was certified as a heart attack.)

# Declaration of Authorship

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

Hannah Piekarz

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A thesis is the product of a lifetime of personal growth, learning, losing and being supported.

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# Dedication

This thesis is dedicated to all the amazing aunts and wise uncles.

In particular, I dedicate this to my uncle, Steve Finney.

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# List of Abbreviations

| | |
|---|---|
| AMI | Acute myocardial infarction |
| ACE | Angiotensin-converting enzyme |
| CVD | Cardiovascular disease |
| CHD | Coronary heart disease |
| COREQ | Consolidated criteria for reporting qualitative research |
| COVID-19 | Coronavirus disease – 2019 |
| ECI | Enhanced cognitive interview |
| GP | General practitioner |
| GT | Grounded theory |
| HAPA | Health action process approach |
| HIV | Human immuno-deficiency virus |
| IPA | Interpretative phenomenological analysis |
| NHS | National Health Service |
| NICE | National Institute for Health and Care Excellence |
| NSTEMI | Non-ST-elevated myocardial infarction |
| PRISMA | Preferred reporting items for systematic reviews and meta-analyses |
| SAGER | Sex and gender equity in research |
| STEMI | ST-elevated myocardial infarction |
| TDF | Theoretical domains framework |
| TPB | Theory of planned behaviour |
| UK | United Kingdom |
| WHO | World Health Organisation |

# List of Appendices

# Substantial Papers Produced from this Research

This thesis contains five papers written for publication. To date, the output of this research is described below. Author contribution described using Contributor Roles Taxonomy (CRediT) (McNutt et al., 2018). The full published copies can be found in Appendix E.

**Paper A) A Systematic Review and Meta-synthesis of Qualitative Studies of Taking Medication for Secondary Prevention of Myocardial Infarction**

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Author Contribution:

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**Paper B) A Phenomenological Analysis of the Experience of Taking Medication to Prevent a Further Heart Attack**

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CL: Supervision, writing – review and editing.

PD: Conceptualisation, methodology, supervision, validation, writing – review and editing.

### Paper C) Reaching 'plain sailing': A grounded theory study of the experience of taking medication to prevent a further heart attack

Submitted for publication to journal *Health Expectations.*

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### Paper D) A narrative analysis of the experience of taking medication to prevent a further heart attack

Manuscript in preparation for submission.

### Paper E) A pluralistic qualitative analysis of the experience of taking medication to prevent a further heart attack

Manuscript in preparation for submission.

# Abstract

Following an acute myocardial infarction (AMI), patients are prescribed a regime of cardio-protective medicines to prevent recurrent cardiovascular events and mortality. This is recommended in international guidelines as clinical evidence shows improved long-term outcomes for patients who receive optimal therapy. Medication adherence in this patient group is poor, and current interventions such as physical memory aids or psychological motivational patient interviews have made improvements, but a single practical intervention with a significant effect to improve adherence has yet to be developed and implemented.

Medication adherence comes from a complex set of behaviours, and this study aimed to better understand the beliefs and experiences of medicine-taking in this group of patients. Semi-structured interviews were conducted with people who take medication to prevent a further AMI, recruited from cardiovascular support groups and also within the University. Data was analysed using three methods in order to obtain multiple perspectives and a richer, more in-depth set of results. Interpretative phenomenological analysis was used to better understand the experience from a patient's perspective, grounded theory analysis was used to model the processes involved in adherence to medication following AMI, and narrative analysis to illustrate the personal, social and system related interactions that people attach to their medication-taking behaviours.

The phenomenological analysis found participants compared themselves to other patients, knowledge was important to them, the future was an unknown, and they described how they built a medication-taking into their lifestyle. The grounded theory study found that participants built a routine on returning home, by which they aimed towards achieving a continuing stability phase, but they balanced the medication-related pros and cons that they encountered, which led up to reaching a crisis point where they required medical assistance. The narrative analysis highlighted the personal and detailed stories that participant experienced, and found a similar shape to the grounded theory study. It added upon this, to highlight that participants considered medication taking as a cumulative protection, and weren’t concerned about single missed doses. These results detailed what the medication-taking experience was like for these participants and offered suggestions of the changes that were required of them to achieve adherence. The level of detail described by participants and individual meaning suggests that intervention work is indicated on a personal basis. However, themes were present, such as the development of side effects leading up to a crisis event, which could help prepare patients more generally to plan for this event taking place. The results of this study could assist with understanding the problem of non-adherence in this group and inform the design of an appropriate intervention to improve medication adherence following an AMI.

# Chapter 1: Introduction

## Cardiovascular Disease

Cardiovascular disease (CVD) is the broad term for diseases that affect the heart and blood vessels. It includes coronary heart disease (CHD), where the arteries become blocked and can lead to heart attack, stroke, peripheral artery disease and congenital heart defects (National Heart, Lung, and Blood Institute, 2015). CVD is the leading cause of death in Europe, accounting for an estimated 4 million deaths, ahead of cancer, the second largest cause of deaths (Townsend et al., 2015). Of the cardiovascular diseases, myocardial infarction, colloquially called a heart attack, is responsible for the largest proportion of these deaths, estimated at 15% of all deaths worldwide (Chadwick Jayaraj et al., 2019). In 2019, the World Health Organisation (WHO) estimated that globally 100 million people were affected by ischaemic heart disease, and was the cause of death of 9 million people (Ferrero & Ferrero, 2023).

A common cause of CHD is the atherosclerosis of the coronary arteries, where fatty deposits build up on vessel walls, leading to a narrowing of blood vessels, and reduced blood flow. An acute myocardial infarction (AMI) is an acute, severe manifestation of CHD, a result of an atherosclerotic plate breaking off and developing into a clot thrombus. This clot can block or partially block the coronary artery resulting in reduced blood flow to the heart. This reduction in blood flow can cause ischaemia, reduced function of the heart ventricles and myocardial cell death.

The artery blockage can be assisted by the surgical insertion of stents to help maintain the opening of artery. If this is insufficient, coronary bypass surgery can be performed involving the transplant of veins and replacement of the occluded blood vessels.

AMI can be further separated into types following the traditional diagnosis according to electrocardiograph measurements into ST-elevated myocardial infarction (STEMI) and non-ST-elevated myocardial infarction (NSTEMI). Today, the diagnosis of AMI involves the measurement of myocardial ischaemia along with the detection of abnormal cardiac biomarkers in the blood (Thygesen et al., 2019).

There were 188,000 admissions due to a heart attack to National Health Service (NHS) hospitals in the United Kingdom (UK) in 2014/15, which equates to one admission every three minutes or 530 daily admissions (British Heart Foundation, 2016). It is believed there are just under one million people living in the UK having survived an AMI (Bhatnagar et al., 2015). In England, the incidence and mortality rate from AMI has fallen since the 1980’s, in line with trends in developed countries. This is thought to be due to implementation of advice in coronary risk factors such as reduction in smoking and dietary improvement, coupled with advances in acute treatment of AMI, which mean improved survival rates. However this potentially increases the number of people at high risk of a subsequent AMI and hospital readmission (Wright et al., 2022) . The same study also found increases in incidence of AMI in younger age groups of men and women, which is of concern as the population longevity increases, there is a subsequent morbidity level rise. Similarly, mortality from CVD in the UK is declining, with 60% of the decline through reducing modifiable individual risk factors, mostly stopping smoking, and the remaining 40% being attributed to improvements in drug treatment. However, the morbidity of CVD is increasing, causing a significant burden on healthcare costs. CVD was estimated to cost the NHS in England £7,880 million in 2010 (National Institute for Health and Care Excellence, 2018).

Atherosclerosis develops insidiously over many years and is severe by the time it produces symptoms in a patient (Novo, 2012). AMI can present as symptoms of chest pain, difficulty in breathing, and arm pain, which are traditionally well-known symptoms, and  important for patient self-recognition and prompt transfer to healthcare services (Birnbach et al., 2020). There is a gender disparity in symptom presentation, and women are more likely report less well-known symptoms such as neck and stomach pain and palpitations (Shin et al., 2009).

Many factors influence an individual’s risk of developing CHD, and include fixed physiological factors such as age, sex, ethnicity, and genetic predisposition. The risk factors that patients can modify are of more interest to disease prevention efforts, and include raised blood pressure, a raised blood lipid profile, obesity, diabetes, and smoking. An individual’s risk in this regard can be quantified using risk assessment tools, which are used to decide, for example, at what level of drug intervention a patient ought to be treated as a preventative measure. In the UK, relevant guidelines are produced by the National Institute of Health and Care Excellence (NICE), NG238, (National Institute for Health and Care Excellence, 2023), covering treatment protocols for all healthcare providers, as the best practice based upon evidence from systematic reviews.

NICE proposes that post-cardiac event, patients should be on a regime of five medicines as standard practice and be issued a management plan. This plan involves enrolment on a cardiovascular rehabilitation programme, where patients are given advice on healthy lifestyles, diet, physical activity, and psychological and social support (National Institute for Health and Care Excellence, 2018)

## Drug Treatment

The NICE guidelines state that after an AMI, patients should be prescribed an angiotensin-converting enzyme (ACE) inhibitor, aspirin and another antiplatelet, a beta blocker, and a statin drug (NICE, 2020), as described in Table 1.

Table 1. Drugs recommended by NICE to be taken post-AMI

| **Medication group** | **Examples of drugs** | **Mode of Action** | **Common Side Effects** |
|---|---|---|---|
| ACE inhibitor | Lisinopril<br>Perindopril<br>Enalapril | Prevent vasoconstriction by stopping ACE I converting to ACE II | Postural disorders<br>Muscle cramps<br>Visual disturbances |
| Antiplatelet | Aspirin | Prevent blood clots by inhibiting action of COX-1 enzyme | Gastric irritation<br>Haemorrhage |
| Secondary antiplatelet | Clopidogrel<br>Ticagrelor | Prevent blood clots by inhibiting ADP receptor | Diarrhoea<br>Haemmorrhage |
| Beta blockers | Atenolol<br>Bisoprolol | Relax cardiac and smooth muscle | Bradycardia<br>Dizziness<br>Cold extremities |
| Statins | Atorvastatin<br>Simvastatin<br>Pravastatin | Alter lipid profile of blood | Joint pain<br>Muscle ache<br>Gastrointestinal upset |

Adapted from (Joint Formulary Committee, 2021)

This evidence-based practice is also endorsed by the European Society of Cardiology (Arslan et al., 2018), the American College of Cardiology and American Heart Association, (Amsterdam et al., 2014). The rationale for the use of these medications was supported by evidence for their individual benefit as a monotherapy, but more recently a meta-analysis of these drug groups concluded that the reduction in all-cause mortality and cardiovascular events was due to an additive effect (Ma et al., 2019). While this study included the broader group of CHD patients, the results state that five-drug therapy confers a 40% reduction in mortality and 25% reduction in cardiovascular events.

This meta-analytic study is important as it shows that the omission of one medication group has a greater reduction of protective effect than that of missing out the group when taken as monotherapy, an effect which is multiplied when more than one drug group is omitted from a patient’s treatment regime-protective effect is maximised by precisely following the regime of medicines prescribed.

## Medication Adherence

Medication adherence is the extent to which a patient behaviour follows that recommended by a healthcare professional who has prescribed the medication. It requires the professional and the patient to work as a partnership to achieve mutually agreed outcomes. Reduced adherence is the result of many complex factors, and the World Health Organisation (WHO) classifies these to those caused by socioeconomics, the healthcare team or system factors, disease-related factors, patient-related factors and therapy related factors. Within this report on adherence, the editor suggests that “Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments”(Sabaté E., 2003). This means that seeking ways to improve adherence could be more beneficial on populations than research into new medicines. This document also contains a section illustrating the role of pharmacists in improving patient adherence and summarises that the profession is important for helping patients adhere to long-term therapy.

Adherence is the current preferred term to describe this behaviour, but this action has previously been described as patient compliance and concordance, but replaced since, in order to emphasise the patient's active role in this process. However, it is important to note the terminology change when searching literature.

Similarly historic, the standard measure of adherence is considered sufficient at 80% and over of medication doses to be taken. This originates from a study using blood pressure recordings of patients taking medication for hypertension, where a regression analysis found that diastolic blood pressure was impacted below the figure of 80% adherence (Brian Haynes et al., 1980). More recent research has questioned the clinical appropriateness of this figure, but it remains in widespread practical use (Baumgartner et al., 2018).

The most recent Cochrane review study of adherence concluded that there was a lack of effective interventions, with current interventions producing modest gains in adherence (Nieuwlaat et al., 2014). They posit that a lack of feasible long-term interventions and a failure to detect clinical outcomes of adherence may be the cause. These findings support the requirement for better adherence models to be found.

Adherence is not solely an issue for the patient, the prescriber also needs to agree the prescription with the patient and provide support for the patient's needs. Improving adherence is not about getting the patient to take more medicines, but begins with understanding the patient's perspective of their medicines and the reasons why they may not wish to or be able to take them (Nunes, V, Neilson, J, O'Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009).

This report discusses how adherence can be viewed as either intentional, where the patient makes an active decision not to take their medicine, or unintentional, where the patient intends to take their medication, but are prevented from doing so by issues outside of their control, such as forgetting to take it, not understanding the instructions, or being able to recall them, difficulty in administering the medication, or being unable to pay.

There have also been further classifications, such as primary non-adherence, where the patient fails to begin their treatment, and secondary non-adherence where the initial prescription is filled, but then not taken as prescribed (Vermeire et al., 2001). Another model proposes that non-adherence is defined as non-initiation, non-implementation, and non-persistence (Vrijens et al., 2012).

It is a challenge to measure adherence because it is a function of individual behaviour. Subjective recording is measuring from people’s activity; when patients, their families or caregivers are asked about their medicine-taking, using assessment tools such as a Morisky measurement scale. Studies of self-reporting have found that patients are liable to over-estimate their adherence, unless they see no response to their treatment (Bosworth, 2020). Objective recording uses physical evidence to measure adherence, such as counting doses taken or paper audits on refill of prescriptions. Biochemical measurements can also be used to assess adherence through direct drug assay, or the measurement of biomarkers in urine or blood samples. These methods have also received criticism as true levels of patient adherence remain unknown, as the measured end products are liable to patient pharmacokinetic factors (Lane et al., 2019) . A systematic literature review of the measurement of adherence found that there is no overall guidance or agreement amongst researchers, but the approach used ought to match the behavioural aspect that studies wish to measure (Kronish et al., 2021).

Throughout literature, there remains an interchangeability in reporting the term, where medication adherence and non-adherence are used as dichotomous binaries depending upon the context, where perhaps behaviourally they ought not to be, and ought to be viewed and addressed differently.

If the number of medications is difficult for patients to manage, a polypill made up of multiple drugs proposed as an aid to simplify a patient’s regime. A recent Cochrane review of studies assessed how using a single pill that contained a combination of all the medicines used to prevent cardiovascular events affected patient outcome in terms of mortality and morbidity, and the conclusion was uncertain of the patient benefit (Bahiru et al., 2017).

Another approach is to give patients more reminders to take medicine. This could be done by the physical arrangement of having drugs laid out in a tray, for example in a NOMAD or Dossett systems, or prompts could be issued to patients, through charts or by alarm reminders. Another Cochrane review of studies assessing the use of  mobile telephone text messages as patient prompts to take cardiovascular medication using adherence measures as well as mortality and morbidity to assess showed promising results, but was limited by insufficient evidence, citing seven studies with 1310 participants (Aj et al., 2017).

These studies all contribute to the knowledge of measurement of adherence, but are quantitative in their rationale, where a research question is developed based on existing theories, a hypothesis is proposed, and a study designed to measure the change in variable outcomes. As no significant intervention has been found yet, this could indicate that studies are asking the wrong types of research question, and current theories are overlooking factors that are important to real life patients.

## Medication Adherence in Post-AMI Patients

In cardiovascular patients, primary nonadherence, which is not filling the initial prescription, has been shown to lead to a significant increase in one-year mortality rates following hospitalisation for a heart attack. Secondary non-adherence, which is failure to follow the instructions or refill the prescription has been shown to increase one-year mortality, hospitalisations and costs (Baroletti & Dell’Orfano, 2010)

A meta-analysis taking data from 376,162 patients found that the level of adherence in patients taking medication for secondary prevention of AMI was 66% (Naderi et al., 2012). This was higher than the level of adherence of 50% in the comparative group taking medication for primary prevention, who had not had an AMI. This study also found that there were no other statistically significant differences between the drug classes, which suggests that side effects are not the main cause of non-adherence.

A study of 4,394 real-world post-AMI patients found a high proportion of patients fell into the lower adherence group of <80% adherence. However, in the patient group that recorded an adherence of >80%, a significantly reduced all-cause mortality was found, along with a reduced risk of further major coronary events (Huber et al., 2019).

A study of post-AMI patients in France found that non-adherence was greatest in patients over 74 years of age, those with multiple diseases and those covered by full healthcare payments due to low income (Tuppin et al., 2010). The study found that prior use of the drug regime and surgical implementation of a coronary stent increased medication adherence. This study considered adherence to be cover with a prescription of >80% of time.

A Chinese study in this patient group that used the benchmark of 90% as measure of adherence, found that 52% adherence was recorded over one year. That study also found that patients had a lower risk of further AMI events in those that observed good adherence. In patients with poor adherence, the participants described the belief that they were cured, or medication was no longer required. This poorer adherence group were also found to have more co-morbidities and lower education status (Shang et al., 2019). Another study found that the rate of prescription for guideline-directed medications for AMI was inversely associated with in-hospital mortality

(Nakao et al., 2019). Both studies show the importance of good adherence due to the link to reduced risk of further AMI events and lower mortality rates.

With regards to single drug groups in this patient group, a study of antiplatelet adherence post-AMI was undertaken to ascertain the agreement and accuracy of patient reported adherence by comparison of fill rates against blood serum drug levels (Fanaroff et al., 2020).The study found agreement between fill rates and patient reported adherence, and also that patient persistence was poor, with 13.5% of participants classed as non-persistent after 30 days. In the study, non-persistent patients experienced a higher rate of 1-year adverse cardiac events.

A study of adherence to beta-blocker medication in this patient group found that continuous regular use reduced major adverse events to 36% compared to patients who took no drug (Won et al., 2020).

A study of statin adherence in patients already taking the drug prior to their AMI, again found that poor adherence led to increased mortality (Khalaf et al., 2021). However, another study also found that in patients who increased their statin adherence following an AMI, the resulting reduction in mortality was the same as those whose adherence did not alter pre and post-AMI (Hickson et al., 2019). This finding means that the beneficial effect of statin adherence on mortality can be obtained following initiation of medication adherence and is comparable to those participants who continually adhered to their medication. Another longitudinal study of statin adherence found that over 10 years, by the final 5 years 12% of patients were not taking their lipid lowering therapy (Huynh et al., 2018).

A study of all groups of post-AMI medications (hypertensives, statins, anti-platelets and anti-coagulants), measured participants’ persistence using prescription fill gaps, and adherence using number of days coverage. The study found 20% of patients discontinued medication within 90 days, and 50% within the first year, however, when they were persistent with therapy they were also adherent (De Oliveira Costa et al., 2023). The study found that by three years after initiation, persistence was generally low, ranging from 17% to antiplatelets to 37% to anticoagulants. The study found adherence and persistence increased with participant age and the number of cardiovascular medications prescribed.

Similarly, another study compared length of AMI medication prescription refill, and found that 12-month adherence was higher in patients who were provided 90-day refills in comparison to those given 30-day refills, which was consistent across medication classes (Rymer et al., 2021). The prior treatment of patients taking AMI medication was found to be a predictor of good adherence, and treatment naïve patients were found to be less adherent; those taking lipid lowering or renin-angiotensin blocking drugs prior to their AMI were found to be nine times more likely to be adherent at 12 months post-AMI (Campain et al., 2022).

A study of medication adherence in the broader group of coronary artery disease patients, including angioplasty and angina patients, found self-reported adherence to be 56% (Khatib et al., 2019). They found greater rates of adherence in female patients, and with increasing age, and that aspirin was the only medication that had a significant association with non-adherence. This multi-component study also featured a survey where patients could add responses, which found that they gave reasons for non-adherence as forgetfulness, worry over doing more harm, feeling of being hassled about sticking to a plan, patients stopped taking medication without informing their GP after feeling worse, and were not convinced about the importance of their medications.

These studies show that adherence to evidence-based practices in drug treatment can improve mortality and morbidity when taken for secondary prevention of AMI. Factors involved in good adherence include longer refill gaps (i.e. greater medication quantity supplied), a greater number of medication groups to take, and prior drug treatment. Adherence was also found to increase with patient age, with little difference found between male and female patients. It follows that this will also reduce the burden onto the healthcare system and associated costs. However, none of these studies have been conclusive in finding the cause of non-adherence in this patient group.

The variation of methods and results in adherence studies show that adherence is complex and difficult to measure for the purposes of research. Perhaps a standardisation of the measures would provide researchers with more clarity of method to enable direct comparison. This is the first criticism in a report which questions current practices in adherence (Gellad et al., 2017), who conclude that measurements of adherence need to be clear and so the tools for measurement are an appropriate match for them, which would make systematic reviews easier to perform. The report concludes that current thinking implies that adherence is a simple, static construct for the purpose of measurement, when it is not in practice. The authors ask for a clear taxonomy of adherence to enable the advancement of work in this area, and that perhaps we need to better define the terms and distinguish between the forms of non-adherence.

Similarly the results of this literature summary have shown that whilst there is plentiful and deep interest in research on this subject, yet little evidence for the theoretical basis of these studies, and evidence of the factors involved in adherence. All of the research prior has used empirical means to quantify and determine scales of the issue, yet little research exists on the causes and factor involved for patients taking medication for secondary prevention AMI, and so it could be claimed that current research is based upon presumed factors, thematically within the WHO factors. This indicates that a qualitative study into the factors for this group of patients is indicated in order to validate and focus further research into appropriate fields.

## Health Professionals and Pharmacy

The multidisciplinary healthcare team can have an input to improve medication adherence, and pharmacy is well-situated to deliver useful interventions, both within the healthcare system framework and for patient accessibility of services. In a systematic review, the role of the pharmacist as part of a multidisciplinary team to provide effective cardiovascular patient interventions was confirmed by showing an improvement in therapeutic outcomes and human outcomes such as adherence, satisfaction and knowledge in some studies, (Omboni & Caserini, 2018). Community pharmacy has moved away from traditional roles like dispensing to become an accessible means of a variety of healthcare services, provided by a skilled professional pharmacist with patient-centred practice at its core. In the UK, remuneration for pharmacies is now linked to a range of services that include healthy lifestyle promotion, disease prevention, medicine management and medicine adherence (DoH, 2008). Cardiovascular disease is a target group of the New Medicine Service, which takes the form of a consultation with patients to identify issues that they may have with adherence in order to help patients manage their medicines better (NHS England and NHS Improvement, 2021). In the UK, the Five Year Forward Plan supported the need for changing the models of care within the NHS (NHS, 2014). It supported the integration of pharmacists within general practitioner (GP) surgeries, to supply medicines management services and better integrate patient care. The future of the profession of pharmacy is focused upon disease management, improving public health and improving transfer of patient care. Pharmacists are suited to providing interventions to support patients with their medication adherence. In a systematic literature review of pharmacist interventions that supported patients taking medication for secondary prevention of CHD transferring between care in hospital and returning to a home setting, interventions reduced hospital readmissions and improved medication adherence (Weeda et al., 2021). In the UK, the role of advanced clinical pharmacist in providing specialist post-AMI medicines optimisation clinic services has shown promising patient feedback in supporting patient adherence (Price et al., 2023).

In a report discussing the pharmacy support of patient adherence, the routine interventions used were criticised as being educational or behavioural, such as reminder prompts, regime simplification, or increasing patient knowledge (Easthall & Barnett, 2017). These interventions are practical in nature and as such, easy to address in the pharmacy. The authors call for further studies into the causes of intentional non-adherence, such as health beliefs, patient self-confidence and motivations. This is in line with the development of roles for pharmacists to provide patient support through practices such as motivational interviewing and health coaching.

These behavioural supports are tailored to the patient and reflect the report’s message that there is no single universal approach to the issue of adherence.

In one of the first UK studies using pharmacists in one of their newer roles, an evidence-based behaviour intervention was successfully implemented for patients with multiple cardiovascular risks to give a meaningful improvement to their health (McNamara et al., 2015). Home medication reviews were provided to patients, where treatment and behavioural goals were identified through pharmacist assistance. Whilst this study has a positive outcome, the health improvements seen are not attributable to a single health or lifestyle change, and so could be due to varied proportions of improved medication adherence, or improved lifestyle choices made by the patient. However, it supports the idea that pharmacists are appropriate professionals to be doing this work with patients.

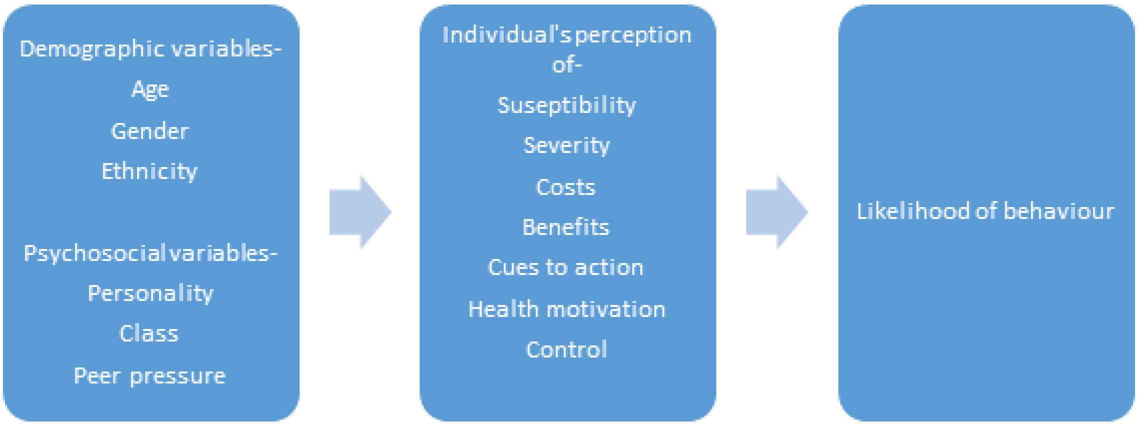
As illustrated above, however, no definitive intervention to tackling medication non-adherence has been found. Perhaps this is because adherence is a complex multi-faceted issue. This necessitates a different approach, such as one that takes account of the multifactorial nature of medication non-adherence by exploring fully the social and psychological drivers of this behaviour.

## Health Behaviours

The WHO defines health as a complete state of physical, mental and social wellbeing. This definition acknowledges that illness, or reduction of health, is a complex issue, and to describe illness as is the traditional Western approach in terms of the physical state is to over-simplify. Patients impose their own psychologies and social influences on their health, which also need to be addressed to progress a patient towards more positive state of wellbeing.

Patients influence their own cardiovascular health risks by their behaviours. They can take risk-increasing decisions, such as smoking, being obese and having a high level of alcohol intake. They can also make choices to improve their health, such as following their medicines regime and embracing an exercise routine. These health behaviours affect patient’s lifestyles not only prior to illness but are just as important when a patient faces a chronic illness and how they cope with and manage their disease, including adherence behaviours.

A review of the breadth and processes involved in adjusting to chronic illnesses found that multiple factors such as social, cognitive, emotional, behavioural and physical components all played a role in the change, and that these factors are interrelated and influence one another (Stanton et al., 2007). One of the earliest health behaviour models, the health belief model, was developed through the 1960’s (Rosenstock et al., 1988). It assumes that the balance of people’s beliefs about a risk associated with a disease and their perception of the benefits of taking a preventative action will determine their readiness to adopt the desired behaviour.



Demographic variables-
Age
Gender
Ethnicity

Psychosocial variables-
Personality
Class
Peer pressure

Individual's perception of-
Susceptibility
Severity
Costs
Benefits
Cues to action
Health motivation
Control

Likelihood of behaviour

Figure 1. The Health Belief Model (Becker & Maiman, 1975)

An integrated theory of behavioural change which can be applied to health and medical contexts has been developed, combining the Reasoned Action Approach and the Theory of Planned Behaviour. The theory proposes that the variables important to health behaviour are intention, attitude, perceived norms, perceived behavioural control, behavioural beliefs, normative beliefs and control beliefs (Fishbein, 2008).

Instead of considering change to be a sudden event, the transtheoretical model of behaviour change considers that change is a course of action that progresses through stages, rather than a linear model with a start and endpoint (Prochaska, 2008). It implies that a different intervention is appropriate for each of the first five stages of the change.

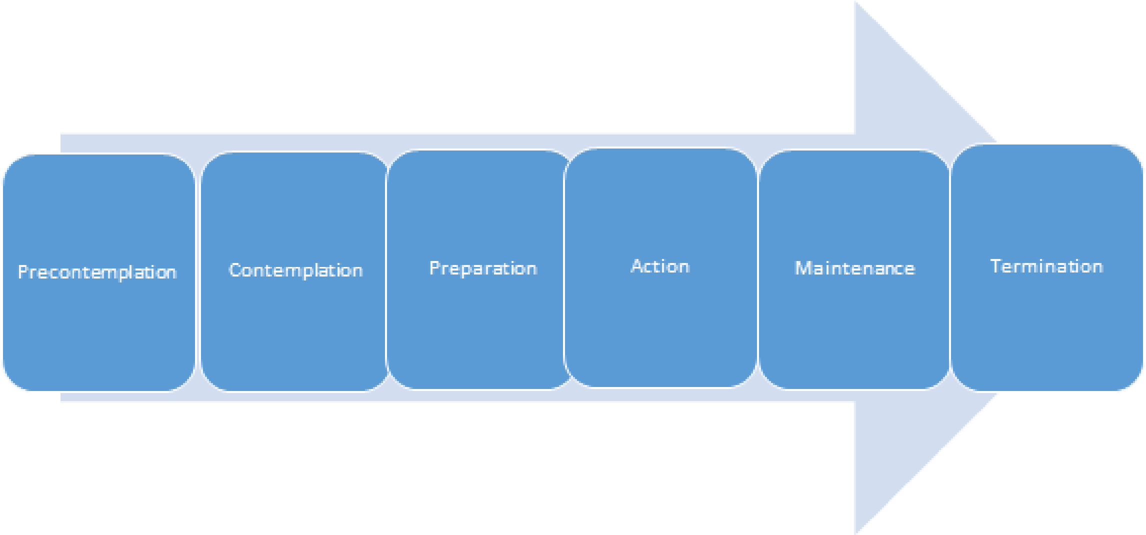


Figure 2. The transtheoretical model of change (Prochaska, 2008).

All the behavioural theories proposed so far have assumed an analytical relationship to the factors involved, the decision made and the behaviour as outcome. They assume that the human process delivers a perfect outcome, when humans are not machine-like in their action, and apply emotions and thoughts to their logic. People make decisions that appear to be irrational to others, and fuzzy trace theory (Reyna & Brainerd, 1995) accounts for this. The theory proposes that the representation of information influencing a patient has two forms: gist and verbatim. Gist is the fuzzy, qualitative side and is influenced by emotions, education, culture and experiences, whereas verbatim is the accurate, quantitative information.

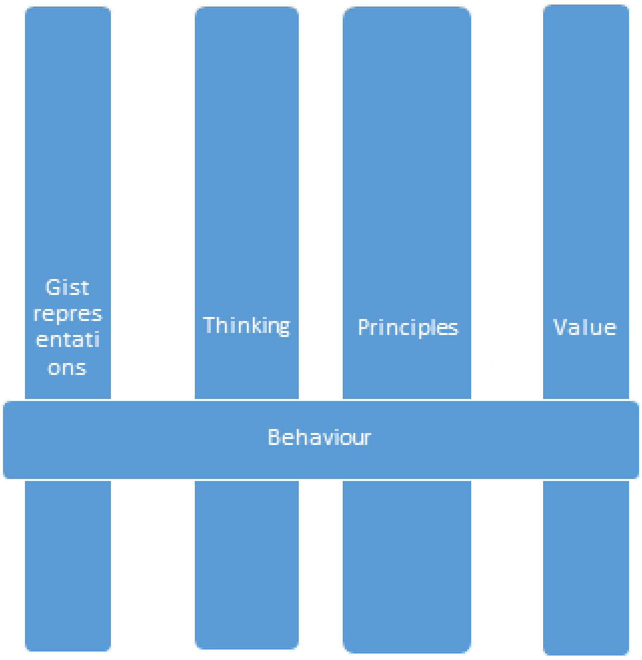


Figure 3. The important concepts in fuzzy trace theory (Valerie F. Reyna, 2008).

Another anomaly in these theories happens when a patient has an intention to make a behaviour change, but don't continue to action the intention. This is due to post-intentional barriers. The Health Action Prevention Model (HAPA) (Schwarzer, 2008) comprises a series of two self-regulatory processes; intentions, which are goal setting, and volitions, which are goal pursuing. The HAPA model considers patient self-efficacy, and interventions can be tailored to a patient's mind-set.

In endeavouring to produce a psychological model that could encompass all behaviours, the COM-B model was proposed (Michie et al., 2011). It comprises three essential conditions of capability, opportunity and motivation which need to take place for a behaviour to take place. In studying its application to medicine adherence, (Jackson et al., 2014) conclude that COM-B has advantages over other models of adherence in that it accounts for the wide range of factors that influence patient behaviour, incorporates the dynamic of performance affecting future actions, and has been designed to incorporate interventions. The COM-B model has been used to design an intervention to improve self-care by heart failure patients, using the results of two meta-studies, the factors that were barriers and enablers to patients were defined (Whittal, Störk, et al., 2021), and then the results were tested using Delphi survey to key stakeholders to develop the areas that were important within a practical context for appropriateness (Whittal, Ehringfeld, et al., 2021). The clinical use of this intervention remains to be reported.

The usefulness of each theory in a situation will depend on whether there is evidence to support its use, for example evidence generated through research studies. The theories could be used to help design a patient intervention to change patient beliefs and improve health outcomes. Even when an intervention is found that successfully changes a health behaviour, it is often unclear how it works, and the theory underlying the change is frequently grouped with general theories and so the mechanism of action of the intervention remains ambiguous. An attempt to clarify the action of behaviour change interventions was studied through a meta-review of studies that used self-regulation as a component of cardiovascular behaviour change interventions (Suls et al., 2020), and found that cautious interpretation of results was required, but that self-monitoring showed a promising line for intervention work, but other self-regulatory mechanisms less so.

Another cross-sectional study that aimed to determine factors that were involved in medication adherence to cardiovascular medication, using cardiac rehabilitation patients to self-report using questionnaires based around behavioural change theory. They found that the ability to refill prescription and positive beliefs about medication were important factors that predicted medication adherence, and suggested that these factors are taken into consideration in future intervention design (Al-Ganmi et al., 2020).

One study was found in relation to medication adherence post-AMI (Presseau et al., 2017), which implemented a behavioural model to propose a theory of patient medication adherence. They found that action planning and social support were key predictors of adherence in this patient group. The authors supported further work to develop a novel theory that drew on HAPA and the Theoretical Domains Framework (TDF); the Theoretical Domains Framework helps to describe and identify the factors that influence a behaviour but does not help to explain or suggest causality of the domains (Nilsen, 2015).

A summary review of health behaviour theories was conducted in relation to long-term human immuno-deficiency virus (HIV) and tuberculosis medication adherence (Munro et al., 2007). It found little evidence that theories improved patient's medication adherence, but they were useful in the understanding of adherence behaviour and contributed to the development of interventions. Munro's criticism of the use of models were that they don't account for non-voluntary factors affecting behaviour, that a repeated choice can be an unconscious behaviour, behavioural skills are not addressed, there is no importance on the origin of a belief, and how this influences other behaviours, they ignore power relationships and social reputations, and they focus on a single threat, and don't consider multiple threats competing for attention. These limitations suggest that behaviour models have a place in our understanding of adherence, but that there are many other factors in the real-life situation that affect medicine taking, and perhaps a different approach is necessary to better understand the influences of these factors on patients.

In relation to cardiovascular medicines a new framework for medicine adherence in this patient group has been proposed (Bosworth et al., 2018), which includes time-varying and self-efficacy factors along the initiation, implementation and discontinuation stages of medicine taking. They further went on to characterise patients in their non-adherence behaviour with a view to tailoring an intervention towards groups of non-adherent patient profiles (Blalock et al., 2018). In their study, they found four distinct types of non-adherence behaviours in patients taking medicine to reduce cholesterol; those who forget, those worried about side effects, those with other life events to attend to, and a ubiquitous group who cited many reasons. This suggests that the issue is still a focus for studies and at present, as behavioural theories are still not satisfactory, and further work is warranted.

## Interventions to assist AMI patients with medication adherence

In targeted research to better assist this patient group, a large community based population study of clinical adherence to medication found that risk factor control and lifestyle change were factors associated with long term survival (Solomon et al., 2020). Another study found that intense follow-up in primary care improves patient compliance behaviours in following diet, activity levels and medication outcomes (Lizcano-Álvarez et al., 2023), advocating in the first few months post-AMI, nurse-led self-care training for patients. A recent study found that the input of a clinical pharmacist had no impact on the reduction of further cardiovascular events in CHD patients at 6 or 12 months of the study follow-up (Xu et al., 2019).

A study of a complex intervention using wireless pill bottles, financial incentives and social support for patients did not significantly improve adherence in this patient group, nor improve re-admission outcomes (Volpp et al., 2017)

An intervention that addressed patient behaviour found that the threat and knowledge of the risk of death improved patient knowledge, yet not patient medication adherence (Branda et al., 2022).

There remains to be a useful practical intervention to assist this group of patients with medication-taking, which suggests that further work is required at a more fundamental level to ascertain where issues lie.

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## Summary

As discussed above, a generalisable intervention has yet to be found to be successful, and so it is to more specific groups of patients that we look to study. By tailoring interventions towards a patient group, factors inherent in treatment regimens or the patients themselves could be significant.

To summarise so far, medication adherence has yet to be addressed by a practical successful intervention. To do so would be important for patients taking medicine for secondary prevention of AMI, as following the regime of the combination of five medications will reduce the likelihood of mortality and morbidity in the future. As discussed earlier, perhaps the taxonomy of adherence is the issue, and there are facets to the term ‘adherence’ that need to be separated and clearly defined.

## Rationale for this study

To summarise this introduction, there is a clinical evidence base that taking medication as directed by a prescriber reduces mortality, morbidity and associated healthcare system costs, and this effect is also additive across medication groups, therefore taking all medication as directed is the desired requirement for maximum potential clinical benefit to be obtained.

Medication adherence in this patient group, in line with other medication groups, has been measured as poor, and again, interventions to address patient adherence have gone some way to assisting people to take their medication, yet no intervention has been found that is practical, and has a significant impact upon both medication adherence and long-term clinical effect.

Mediation adherence is the result of a combination of socio-economic-, healthcare system-, disease-, therapy- and patient-related factors. In order to design a successful patient-centred intervention, all of these factors and their influence upon adherence require further study. With an absence of successful all-encompassing medication interventions, the disease and therapy-related factors indicate that it would be appropriate to study the AMI patient groups as a whole to tailor the design of an intervention to this patient and treatment-related group.

Health behaviour theories have yet to adequately model adherence behaviour and so an alternative approach is required to study patient beliefs, influences and process ideas.

This study proposes to address the knowledge gap that currently exists, to find the factors that influence this patient group, and suggest that studying the experience of taking medication following an AMI is an appropriate method to describe these factors. With a better understanding of this experience, researchers could then design more appropriate patient- and treatment-related interventions for patients taking medication for secondary prevention of AMI.

# Thesis Aims and Objectives

The aim of this thesis is to produce a detailed coverage of the themes involved inthe patient experience of taking medication for secondary prevention of AMI.

This will be done through this thesis by:

1) Systematic literature review to find out what is currently known about the experience of taking medication to prevent a further AMI.
2) Produce an accurate, detailed description of the experience of taking medication to prevent a further AMI. Firstly, to produce a close first-person account using a phenomenological approach to gain insight from a person-centred perspective, then using grounded theory analysis to further understand the process that patients experience by modelling the relationship and structure of themes. Finally using a third appropriate qualitative method to add more detail and another perspective to this analysis. Findings will be overlaid to establish if a pluralistic analysis offers another level of depth and furthers our understanding of this experience for patients.

# Thesis Structure

This thesis comprises a collection of published papers, as described in the Substantial Papers section of the preface. It is the intention to continue submission for publication of all the papers produced, and that section details each paper's output status to date. It was important to present this thesis as a coherent body of work, and so structural and design decisions have been made to allow for this. The published papers have been incorporated and formatted within this thesis for aesthetic consistency, and the full published articles can be found in Appendix E.

The thesis has been organised into eight chapters. The first chapter will describe the background to taking medication for AMI, the rationale for the study, and the thesis aims and objectives. In the second chapter, the background to the methodology is explained, along with the aim of the research, and structure of the research, which differs from the thesis structure for reasons described within this chapter. The research design, methods and research reflexivity are described here. A flowchart of the research structure, the research output and its location within this thesis are explained at this point.

Chapter 3 consists of the literature review, ending with a summary of findings and discussion. For presentation reasons, the research papers are presented grouped together in this thesis, whilst the literature review took place part-way through the research stage.

Chapters 4, 5, 6 and 7 consist of the grouped papers produced for publication as a result of this research. Each chapter begins with an introduction and describes decisions made in between studies and adds critical commentary and a reflexivity during this qualitative research, which is often in danger of being overlooked by collation for a 'thesis by publication' approach. Similarly, as a 'thesis by publication', a forewarning that the introduction to each paper will be repetitive, and I apologise in advance for using Dr Sabaté's WHO quote at every opportunity. It is an important one, and therefore the repetition is justified.

Lastly, in chapter 8, a discussion of all the research, bringing the findings together, including a concluding statement of reflexivity, consideration of what this research adds to current literature, limitations, practical clinical and research implications, future directions and finally pulling all these points together, a conclusion of the thesis.

# Chapter 2: Methodology

## Qualitative Methods

To better understand the complex behaviour and beliefs of patients, a qualitative study is appropriate. Qualitative research can draw out mechanisms and illuminate links between variables by looking at explanations or accounts provided by the people involved. It can illustrate how macro variables such as social class, location, or education, become translated into the micro variables such as everyday practices and understanding, to guide individual behaviour. It can provide a better understanding of apparently illogical behaviour (Barbour, 2014).

Qualitative approaches have been used by social scientists to gain an insight into marginal communities such as sex workers or drug users, and anthropologists use the methods to help their understanding of the structure and culture of societies unknown to them. The approach involves generating a research question, which the investigator will explore using sources to gain a deep and rich insight of the human process, emotions and experiences that the question generates in the subject. Qualitative data can be generated through participant observation, interviews, focus groups and analysis of documents.

Qualitative methods are suited to healthcare research as they can offer insights into patient perspectives which can only be explored in this way and also provide a rich range of methods by which to do so (Braun & Clarke, 2019). Similarly, there can be a disparity in understanding between patients and practitioners regarding treatments, which can cause a ‘rupture in communication’, and can be investigated through qualitative studies, aligning with the practice of patient-centred care. Patient perspectives are important in policy making and clinical guideline formation as engagement with stake holders and those with a lived experience of an issue become increasingly important, as the addition of patient views adds to an evidence-base (Utens et al., 2014). The epistemological tension that arises by addition of qualitative research in the development of evidence based practice can be bridged by philosophical pragmatism that recognises that knowledge can be various (Lin, 2023). Qualitative research with patients to develop an intervention that assists them can also be fitted as part of the much larger umbrella term of patient engagement, where patients are asked for input, listening to their response, translating the input into insights and acting to address patient needs (Ashkenazy, 2020) .

Qualitative research has been used to develop the design details of complex healthcare interventions, such as an intervention for secondary prevention of CHD, where participants responses added a useful depth of detail that would not have been obtained in a questionnaire (Corrrigan et al., 2006).

As an effective intervention for adherence has not yet been brought into standard practice, the behaviour of patients taking medication for secondary prevention of AMI requires further investigation and a better level of understanding in order to provide better support for this patient group in taking their medication, and a qualitative study is indicated to provide this.

Qualitative studies vary in their approaches, depending upon the question being researched, but all are based on the notion that society is created by our own actions and the meaning that we attribute to them. We construct meaning out of our behaviour and build knowledge out of the consequences retrospectively.

### i) Grounded Theory

Grounded theory is an approach based up on symbolic interactionism and was developed by Strauss and Corbin from the Chicago School of Sociology in 1967 (Corbin & Strauss, 2012).

Grounded theory relies on data collection and analysis of the text, where the researcher moves back and forth throughout the process. As such, the researcher becomes grounded in the data. By analysis, the data is assigned categories, 'codes', and these codes are constantly compared and contrasted with one another to elicit further meanings and codes.

These categories are then organised to produce a theory of the process. The researcher can then use an emerging theory to direct further data and analysis. The use of extreme cases is desirable to fully explore the research question. The search for further data ends when no new categories can be derived from the data, termed the theoretical saturation point (Charmaz, 2006). This is expected to require approximately twenty participants to reach this stage (N. Frost, 2011).

### ii) Interpretive Phenomenological Analysis (IPA)

IPA is a methodology that explores personal lived experiences to examine how people make sense of their social world. It examines the research subject from the point of view of the participant and draws out the feelings and emotions involved. IPA involves 'double hermeneutics' in that a researcher is trying to make sense of a participant that is trying to make sense of their personal and social world. As a consequence, the researcher needs to remove their own preconceptions and prejudices which could affect their interpretation of the results (Biggerstaff & Thompson, 2008).

The interpretation of the data can be descriptive and empathetic, but also critical and questioning, in ways that the participants may not be able or willing to do themselves.

Analysis of the data involves a close text analysis, along with the researcher's thoughts, ideas, observations and reflections. Extra focus is given to the content, use of language, its context and interpretations. The themes can then be drawn out from these notes using concise phrases that remain grounded in the text. These themes can then be clustered according to their conceptual similarities. An IPA method of analysis will not produce a broad theory that can be applied to everyone, instead, it focuses on the specific details of an individual's experience, and so case studies are appropriate (Pietkiewicz & Smith, 2012). The number of participants in an IPA study tends to be small, as the focus is upon the ideographic, detailed nature of the results which may become lost when larger data sets produce a subsequent loss in subtlety of meaning (Brocki & Wearden, 2006). Previous studies can range from including one participant for sensitive or unusual phenomena (Robson, 2002), (Melendez, 2016), to the use of forty-two transcripts (Clare, 2002). For this research the number of participants was a pragmatic decision; following the first interview, the analysis time taken to achieve a sufficiently detailed level was noted, and then further participants were included according to the estimated time requirement to complete this study within a planned timeframe.

### iii) Discourse Analysis

Discourse analysis studies the use of language to map the relationship between communication, social interaction, understanding and power. It examines how people's dialogue is constructed, on the notion that people construct discourse and are constructed by their discourse. It assumes that people choose how to describe themselves and their world, meanings emerge through social interactions, words and dialogue are a form of social interaction, and that words make things real, gives people identities, memories, intentions and emotions (Yazdannik et al., 2017). Discourse analysis uses participant's narrative, voice, orientation and self-identity as concepts in the study.

Discourse analysis is useful as it acknowledges different people's accounts of the truth will vary depending upon their situation. It includes the political aspect of the subject. Unlike grounded theory, the aim is not to perform a complete analysis of the text, but to understand how knowledge and power are created and used within it. It does not assume that the findings from a sample can be applied to a macro situation (Starks & Trinidad, 2007).

### *iv)* Narrative Analysis

Narrative analysis is the study of story journeys, with the intention to gain insight into the personal, social, and performative elements of a story through how and why it was told. It organises the time order of events and places them as part of the representation and structure of the story. It describes the psychological, social, and cultural context and functions of narratives (Mishler, 1995).

Narrative analysis has been used to study medication non-adherence in older patients taking medication to prevent heart failure, and found that patients didn’t see themselves as being non-adherent, but adjusted their medicines in what they viewed as a method of self-care to maintain their health (R. Meraz, 2019).

A detailed explanation of each method of analysis is found in the results section of this thesis in the following chapters; IPA in Chapter 4, Constructed grounded theory in Chapter 5 and narrative analysis in Chapter 6.

## Qualitative Analytical Pluralism

Each of these methodologies is useful to draw out answers according to the research question posed. It is possible to combine qualitative methods in a pluralistic approach. This could be done to gain as rich an experience as possible, to use the most appropriate tools in relation to the research question to build up a complete picture, or to examine a phenomena from different perspectives (N. Frost et al., 2010). The use of triangulation allows researchers to add depth to their study, to gain better insight into a phenomenon, to illustrate areas that may not have been investigated before, and highlight areas where research is lacking. Frost argues that one framework alone cannot represent the complexity and variety of human expression.

Similarly, other pluralistic studies have found that the use of differing perspectives produces distinct elements of meaning-making, and then layering of each approach creates a rich interwoven picture of the same phenomenon (Josselin & Willig, 2014). Adding to this metaphor, the notion that people’s experiences are multidimensional, can be fragmentary and also contradictory, and so using a single method of analysis cannot always capture all that is present within a phenomenon, and by the use of pluralism, the multi-perspective positioning offers a more holistic understanding of the phenomenon (Tucker et al., 2020). Pluralism moves our analysis towards a more real-world acceptance of human experience, which is messy and laden with uncertainties, in contrast to neat and tidy results, which are an illusory product of aesthetic wishful thinking (Gabb, 2009).

However, caution should be exercised when interpretations may make sense within their own frames of reference, but epistemological tensions could arise when they become integrated or juxtaposed, and care is required in planning to use methods in combination (Coyle, 2010).

This warning has previously been overcome by the use of bricolage in managing multiple interpretations (Kincheloe, 2004), each effectively adding a section to a body of work without the need to directly overlap them, but with clear understanding of how they contribute to the result. The tensions that arise from multiple stakeholder (i.e. the method of analysis) perspectives are of interest for a researcher as further areas of learning (N. Frost & Nolas, 2013). There is a tolerance for this within a qualitative study, as it is not a search for the absolute truth, but the truth constructed out of the participant’s meaning and understanding of a phenomena and the researcher’s understanding of their meaning.

A meta-study of qualitative analytical pluralism was conducted, which systematically analysed and synthesised the theory, method and findings of pluralistic studies to extrapolate new theories and practical implications (Clarke, Willis, Barnes, Caddick, Cromby, McDermott, et al., 2015). Ten studies fitted the meta-study criteria, reflecting the small amount of research using qualitative pluralism available. Concerning theories, they found that it was the use of differing theoretical frameworks that produced the most divergent results. They advocate researchers understand how the epistemology, methodology and procedure will combine to produce a coherent rationale. They state that it is the differences between the various interpretations that can add to our knowledge through this type of work, and concludes that pluralistic studies produce interesting, polyvocal and sometimes diverging meanings from data sets, which have the potential to contribute to knowledge. They conclude that it is a welcome addition to a toolkit, but its significance is not necessarily superior to that of single-study work.

In this study, the IPA approach is the most different approach to the grounded theory, discourse and narrative analysis, which are the most epistemologically similar.

The IPA analysis was conducted first, to allow the researcher to analyse the data with fewer pre-conceived ideas than if this was done later in the order. This is a practice known as ‘epoché’ or bracketing, which the researcher’s own experience and assumptions are removed to allow for noting without judgement or criticism (Biggerstaff & Thompson, 2008). It is for this reason also that a systematic review of the literature was conducted after the IPA analysis in this study but presented first here.

IPA aims to discover a phenomenon that has previously been overlooked (interpretative), while grounded theory, discourse and narrative analysis use the data to construct new notions of processes and social dynamics (constructionist).

In this thesis the research question design was intended to encompass all methodologies of analysis. For the IPA approach to examine the internal personal experience, the grounded theory to construct a theoretical model of the process, and people’s action when taking medication, and then a further method of analysis to possibly enhance our understanding and findings of earlier methods. The intention was to use the same data using different methods of analysis to understand both the phenomena of taking medication to prevent a further AMI, and how the shift in epistemologies of each method affects the result obtained and then how these results could be combined.

This thesis is important to increase the body of work on pluralism in qualitative studies and adds to current knowledge of medication adherence in this patient group. The first method was phenomenological analysis, and then a grounded theory analysis was performed. The final methodological choice was left open to be determined by the results to fill areas of interest or fit to theories or models, and chosen in this case to be narrative analysis. With all methods, attention was paid to the study design to ensure paradigms of quality within each framework were fulfilled through a well-planned methodology.

## Research Aim

The overall aim of this thesis is to use a pluralistic qualitative approach to study patients who have been prescribed medication following an acute myocardial infarction to better understand the psychological and social factors that influence patient behaviour in relation to medication adherence.

However, through the process of this research, there are further areas of interest that will be answered during the course of achieving the overall aim. This thesis will also add to our understanding of plural qualitative methods of analysis, and the knowledge generated is also worth mentioning as it is of pedagogical value to qualitative research.

## Research Questions

Therefore, there are two important research questions that this study will add to current knowledge:

1) What is the experience of patients who take medication for secondary prevention of AMI?
2) What additional knowledge is obtained from qualitative analysis using plural research methodologies of the same data?

## Research Structure

This research will be conducted with the IPA study completed before and further research takes place, in order to bracket off the research and assist with both a close first-person analysis and prevent any predetermined ideas or judgements being exposed to the researcher prior to this analysis, and unduly influencing the result. Following this, the systematic literature review, grounded theory analysis, narrative analysis and pluralistic analysis will be conducted. The chronological order of the research, the papers produced and their fit within this thesis is illustrated in figure 4.

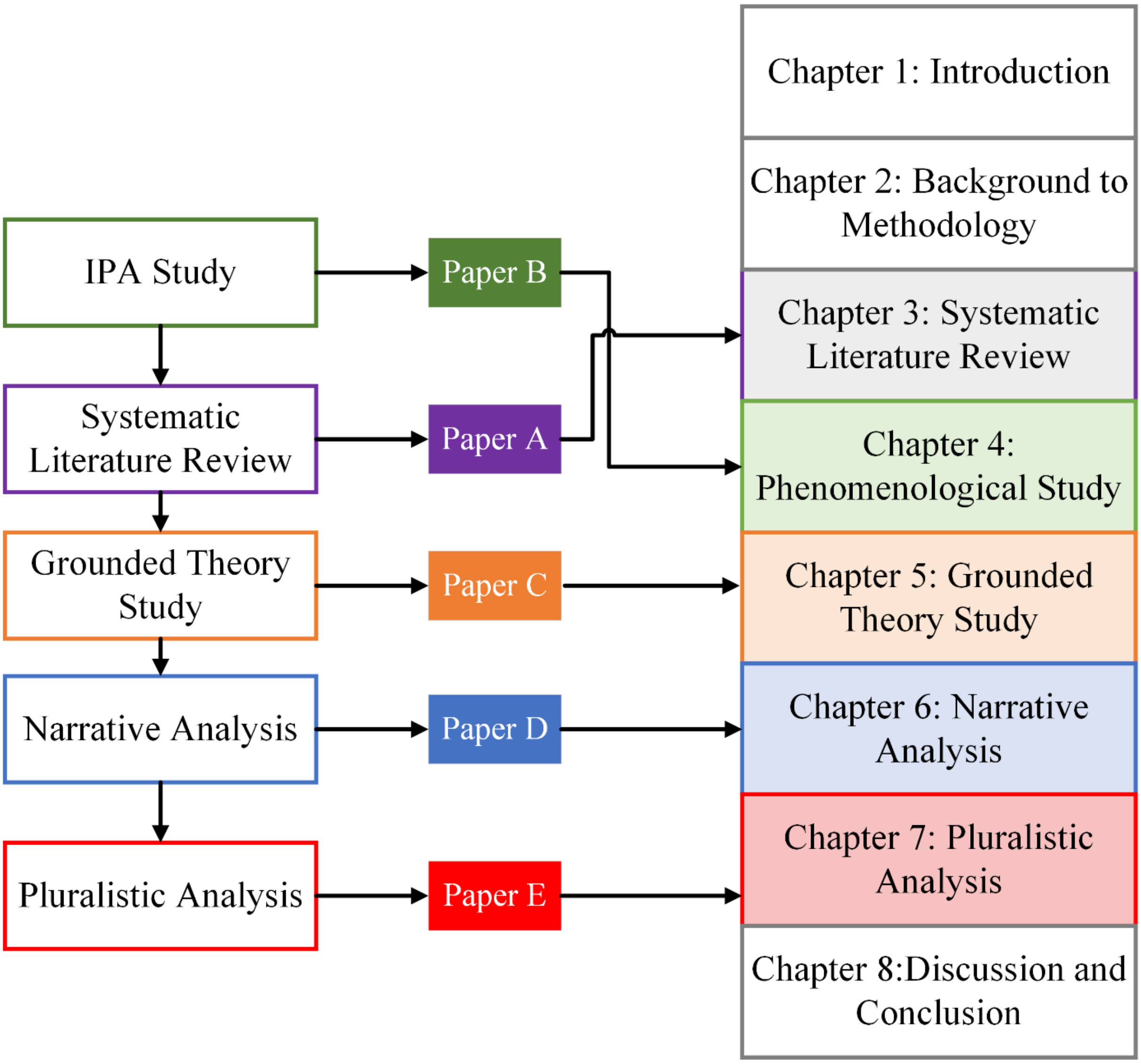

Figure 4. The structure of this research in relation to the papers produced and location of this output within the thesis

## Method

Ethical approval was obtained from the University of Reading Research Ethical Committee, (UREC 18/36). Participants were recruited to the study with the inclusion criteria of people who have been prescribed medicines for secondary prevention of further events following one or more episodes of acute myocardial infarction. Initially, a poster advert requesting for participants was sent by email within the University, with distribution to the public. Following this, cardiovascular support groups within central and south of England were targeted and emailed with the poster for distribution within their membership. This was preceded by an introductory telephone from the main researcher to ascertain interest and obtain verbal permission to promote the study to their group, which was then done by this membership contact. Prospective participants contacted the main researcher by email, and were sent a research information sheet and consent form. On return of signed consent, participants were recruited into the study and pseudonymised. Participants were invited to interview at a time and medium of their choice; in person, by telephone or online, at least a day away from returning consent to allow them reflection and preparation time.

Interviews were conducted by the first researcher, in a quiet office. An interview question schedule was devised and used in a pilot interview, the data of which was used in the study, and revised following review. Interviews were audio-recorded, and then transcribed to text using Microsoft Office software. Transcription was verified for accuracy by concurrent playback whilst reading with the text. Participants were returned their transcripts and offered to make comment.

Participant rapport was important, and considered before interview, by keeping contact with the same researcher, during interview, and following, with communication as how the study was progressing, and contacting participants to share findings. To enable an equitable and fair study, participants were not offered a payment as reward, but treated with reciprocal care, gratitude and professionalism throughout their interaction with the research team.

The data from the first four participants, including the pilot interview, was analysed using an interpretative phenomenological analytical framework (J. A. Smith et al., 2009). This was a case study approach, with the number of participants intuitively decided consistent with timeframe required for producing a sufficiently detailed, rich analysis. Data was analysed, and results reported.

The next stage of analytical methodology was a constructed grounded theory analysis (Charmaz, 2006), and further participants were recruited and analysed concurrently, according to the theoretical finding of the data, according to constructed grounded theory methodology. Data saturation was considered achieved following interview with thirteen participants, and then two further interviews confirmed this. The theoretical model was produced for this report.

Following the production of this model, narrative analysis was chosen as an appropriate fit for a further analysis, and the data produced from all fifteen participants was used for analysis by this this methodology (Labov & Waletzky, 1997).

Data was coded, organised and displayed using NVivo12 software, with the first researcher coding all data. For consistency checking, the whole coding for the two first interviews were validated by the second researcher, and the codes compared, contrasted and discussed. After this, themes were validated ongoing through the study for the IPA and grounded theory study and narrative analysis.

The IPA report was concluded and written up, before the grounded theory study began. The results for both studies were represented using rich verbatim quotes from participants. The grounded theory study produced a theoretical process model and category frameworks for each stage of the process. The narrative analysis produced a whole narrative summary for each participant, and the process model was also used to assign the structure of the summary of narrative arcs, which were then grouped by themes. Finally, the results for each method of analysis were overlaid in a final summation of the results, and presented in a table of grouped themes, alongside a description of themes that were deemed to be of extra interest.

## Quality Criteria in Qualitative Studies

Qualitative studies have their own standards of research design in the same way that quantitative studies will ensure validity of results through methods such as ensuring randomisation and repetition of results. The Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014) is a list of 21 items which are considered standards that should be met in a report. The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) is a 32-point checklist of items for qualitative studies to report in order to establish rigour, again based on the need to ensure they are equivalent to other research guidelines, such as CONSORT standards for randomised controlled trials. Setting standards assists the transparency and completeness in reporting so readers can better understand the design, methods, analysis and findings of qualitative work, to enable better comparison between qualitative reports (Walsh et al., 2020). Having reporting standards also moves towards addressing criticism of qualitative work of ambiguity and complexity of research. The COREQ standards were used as a reference when deciding key points necessary in this thesis design, as they were suitable for reporting interview data and single participant studies.

For qualitative research relating to clinical studies in pharmacy practice, the rationale and further ways of ensuring rigour and trustworthiness of results have been discussed in a report (Hadi & José Closs, 2016) . They suggest recording a clear audit trail, including each decision process that was made through the study, including techniques, analysis, interpretations and researcher thoughts through the process. In this study a research diary was kept for this purpose. Within this, they advocate self-description and reflexivity as a tool to better understand your own position. They suggest triangulation; either a close set of data sources, analytical methods or researchers, to reduce the inherent bias of a single source, analysis or researcher. They advocate a prolonged engagement with the participants, to gain trust and establish rapport. In this study, a single researcher was the participant's point of contact throughout, and the research process involved an initial telephone call or email alongside sending out a study information sheet, a follow-up to discuss recruitment further, returned signed consent and then finally an interview. A peer debriefing is suggested, and in this study, done here by an in-depth discussion by the first author with the supervisory team, to discuss theoretical suggestion and assumption, check critical thinking, analysis and evaluation of result. Finally, they promote a description of settings, inclusion/exclusion criteria, sample characteristics, data collection and analysis methods to allow a reader to decide how the conclusions may be transferable to other settings, situations and populations. This study did this by detailed notetaking of methods in the research diary and using COREQ standards when reporting and writing up the paper.

## Interview Framework

Interviews are a useful means of obtaining a better understanding of a participant's lived experience of a situation or event by using participant's own words and perspectives (Mitchell, 2015). In phenomenological research the objectivity of the interviewer requires consideration, as an interview is a dialogue, and always co-constructed by both interviewer and interviewee (Lowes & Prowse, 2001). This is to ensure interviewer bias and preconceptions are minimised.

Little guidance was found in literature searched for interviewing in qualitative studies, they were found to contain general guides to interviewing, including good types of question to ask, avoiding closed questioning, and building rapport (Merriam, 2014) (Silverman, 2017). No semi-structured interview framework for qualitative interviewing was found. A systematic review that worked towards building a framework discussed identifying the requirements of the interview, reviewing previous knowledge, forming a guide interview schedule, running a pilot test and then building the formal interview schedule (Kallio, H, Pietila, A, Johnson, M and Kangasniemi, 2016).

A suitable solution to the question of objectivity was found in the field of communication studies for obtaining evidence, and forensic psychology. In law, the absolute truth cannot be proven, but a body of evidence can be collected, the quality and quantity of which move cases closer to being proven in court. The police need to follow careful guidelines as to what type of evidence can be used, and much work has been done to study the most appropriate framework to gather evidence. By applying cognitive psychology studies to real life participant interviews, police forces have developed techniques that improve information retrieval, detail and accuracy of information reported (Fisher & Geiselman, 1992), who proposed a new interview methodology, the cognitive interview, to obtain the most information from an event in the past. Their procedure produced the highest number of facts recalled with no increase in number of incorrect facts, when compared to hypnosis and standard interviewing (Fisher et al., 1989). It is a set of techniques to be used rather than a formal procedure, and so could be adapted to various applications.

A cognitive interview comprises of the following points: report everything, reinstate the context, report from a different perspective and reorder the narrative. By reporting the detail in this way, the aim is to trigger a key piece of information that perhaps the observer did not consider significant but was present and may build a better picture of the events.

Reinstating the context, interviewees can be taken back to the event physically and mentally, with the aim to evoke the sights, sounds and feelings of the event. This includes emotional context and the concurrent physical activity. This builds on cognitive theory that the memory of an event is comprised of a network of associations and there are several means to cue the memory (Memon et al., 1997).

Using a different perspective and reordering the narrative, increases the cognitive load on the interviewee with the aim to prevent them skipping over assumed irrelevancies.

Further work has developed the cognitive interview into a collaboration between interviewer and interviewee, building on the memory principles, but adding social dynamics, and communication ideas. The Enhanced Cognitive Interview (ECI) improves the subject's relaxation, rapport, and encourages the giving of information and detail through concentration (Fisher et al., 2011).

The ECI is considered the 'gold standard' of techniques and is used by Police forces in England, Wales, Australia and several states in the US. The British legal system uses it for obtaining the best evidence from adults, vulnerable adults and children (Ministry of Justice, 2011) as well as in accident investigations by the Rail Industry Safety and Standards Board in the UK (Rail Safety and Standards Board, 2018).

It was noted the term 'cognitive interviewing' is more frequently found in relation to qualitative studies as an instrument to validate the use of surveys and questionnaires (Willis, 2005). This type of cognitive interviewing is distinguished by mnemonics of 'think aloud' and 'verbal probing'. This is a separate type of interview, but frequently recurs in literature searches.

A search of PubMed, PsychNET and Google Scholar using the search terms "enhanced cognitive interview", "qualitative", "grounded theory", "IPA", "phenomenology" or "discourse analysis" produced only four results of studies that had used ECI within their interview methods. Athlete's thoughts on doping were studied using grounded theory (Woolf & Mazanov, 2017), in an adapted version of the questionnaire design interview style, and so is not the same as the one proposed here. The use of the shower by elderly care home residents was analysed by grounded theory (Westerberg & Strandberg, 2007), the presentation of oral cancer symptoms to professionals was analysed using framework analysis (Brown et al., 2018), and police interviews with women reporting rape were analysed using discourse analysis (Macleod, 2010).

For this thesis, the principles of enhanced cognitive interviewing were used to design an interview schedule. This consisted of an opening statement building rapport and relaxing the interviewee, phrases to reiterate there are no correct answers and that everything that is said is useful. The notion that the interviewee is the expert, and with the interviewer present as a gentle prompt to draw out their valuable information. An invitation to report everything, and reinstating the context, was used to prompt a free narrative by the participants, before the interviewer returned with questions to get further details.

The schedule started with a simple question that interviewees could easily answer and reply to whichever level of detail they were comfortable with, such as, ‘Could you tell me the medicines that take right now?’. This was intended as easy to recollect, making interviewees comfortable with talking at length, and establish that the interviewer is listening with interest, going on to add probing questions at the end of their reply. Further to this, the following questions would locate the interviewee within a single memory, starting at a place, such as returning home from hospital, asking them to describe what events and feelings they experienced at this time. Questions added upon this, the interviewer asking probing questions for further detail. Topics covered included how they arranged their medicine systems from daily to monthly, who else was involved, missing doses, and their thoughts and feelings about medicines. Further lines of questioning could be prompted by earlier answers, and the interview reached an ending, when there were no further lines of enquiry, a general question to the interviewee asking where they think the focus of adherence research should be, and whether there was an important question or topic that the interviewer had missed, that they would like to add.

The interview schedule was created, with topics covering the WHO factors involved in medication adherence, to elicit the patient, disease, therapy, healthcare system, and socio-economic related factors that the participants might use to better describe their experience of taking medication. The interview guide covered topics such as their introduction to starting medications, routine and problems encountered, which were intended to recall specific events in the participant’s s life experience. The interview question schedules were also informed by the finding of current knowledge and evidence gaps found from the systematic literature search. A pilot interview was conducted with the first participant, and reflected upon to create a final version of the interview schedule. Both versions can be found in Appendix B.

# Research Design

The aim of this study was to describe the experience of taking medication for secondary prevention of AMI, and so participants were selected who were taking medication following an acute myocardial infarction, as they could provide a person-focused lived experience of the phenomena under investigation, with single person interviews to enable the discussion of topics that were deeply personal and more likely to be disclosed in an individual setting than within a group interview (DiCicco-Bloom & Crabtree, 2006).At this level of investigation, the research was not intended to ascribe and separate participants according to the measure of their adherence; the aim of this study was to fill all current gaps in knowledge of our understanding of this experience. The data was intended to be comprehensive in its coverage of the experience under investigation. This study chose to recruit and advertise for participants from within the primary care community in the UK to be useful to the nation where the research was based, and where the practitioners used the NHS service and NICE clinical guidelines were relevant for both the patient experience and healthcare professional’s practice. However, it was the whole lived experience that was important to capture from participant’s point of view for this research, and so the majority of recruitment was done to seek participants from community-based organisations, to not be seen as associated with, or ‘medicalise’ the study by linking with either the NHS or primary healthcare providers. Patients were not recruitted, included or excluded based on ethnicity and socioeconomic status, and no comparisons were made between these as this was not the focus of this research. Other studies have explored the relationships between ethnicity, adherence and post AMI outcomes.

Participants were recruited initially from promotion within the University via email, which was used by the main researcher to establish the practicalities of participant recruitment and organisation before broadening the open promotion for participants. The voluntary cardiovascular patient support groups were found from online listings and approached from their contact details. Following informal agreement with group individuals or the group committee, the group contact would then forward the research promotional material to their members. Initially local groups in Berkshire were targeted, with the intention that a face-to-face interview could be offered as an option to participants, then upon receiving no further expressions of interest in participation, the search was extended to participants from voluntary community cardiac support groups within the south of England, and then on to central England. Recruitment continued concurrent with analysis, and stopped when it was decided that data saturation had taken place for the grounded theory analysis.

Prospective participants made direct contact with the main researcher by email.

Semi-structured interviews were used to generate data, chosen for the ability to obtain, rich, detailed data, where topics can be covered with a set of pre-decided questions but with flexibility to explore further ideas generated as a result of new information provided in answers (Adhabi & Anozie, 2017).

## Validity

Qualitative study requires different measures of precision to ensure that validity and rigour of research are upheld. This differs from standards for quality in quantitative research in terms of validity, reliability and applicability, and care is required in planning to ensure that qualitative values are achieved. The criteria of quality of qualitative research differ from quantitative measures suggestion that it is more appropriate to consider validity is replaced by truth value, reliability by consistency, and applicability by generalisability (Noble & Smith, 2015).

Qualitative research acknowledges that multiple realities exist, and definite truth is never obtainable, but through analysis proximity to the truth can be viewed. This truth value can be influenced by researcher's viewpoint, bias of methodology, and the accuracy of representation of participants in description and interpretation of their data.

Consistency measures include the requirement for trustworthiness, achieved through detailed and transparent reporting and a clear decision-making trail when choices were made through the research.

Generalisability requires consideration as to how the results can be applied to other contexts, settings or groups of participants. It is also important to continually consider these standards through the duration of the research (Hayashi et al., 2019).

With this in mind, this project study was planned, and the following points included to ensure the validity of the research, listed in table 2.

Table 2. Strategies for ensuring credibility of this research

| **Measure** | **Defined by** | **Addressed by** |
|---|---|---|
| Truth value | Reflexivity | Reflexivity account<br>Field notes interview journal completed<br>Peer review by discussion of results |
| | Representation of participants | Interview transcripts accuracy checked by audio playback, participants offered comment<br>Reporting verbatim extracts<br>Analysis results available in supplemental material<br>Data triangulation – three methods of analysis |
| Consistency | Auditability | Transparent description of process; planning, method, results, findings |

| | | |
|---|---|---|
| | | Consolidated Criteria for Reporting Qualitative Research (COREQ)<br>Research diary log of methodological, practical and theory notes<br>Theoretical ideas discussed between team, noted and revised ongoing |
| Generalisability | | Description of participants, context |

## Reflexivity

As a measure of credibility of a qualitative study, reflexivity is described as an evaluation of the context and subjectivity that researchers acknowledge arises during the production of their research. It details the personal, interpersonal, methodological and contextual factors that influenced the generation of data. Using the guidelines stated in this report, a statement of reflexivity was completed for this project.

i) Personal reflexivity

*How are our unique perspectives influencing the research?*

I was the primary investigator and first author of all the reports produced for this study, which were conducted as part of my PhD in pharmacy. My colleagues and participants were aware of this research context.

I have lived experience of having a family member taking medication for secondary prevention of AMI, and came to this research with knowledge of healthcare processes relating to AMI. There may have been points within interviews where participants mentioned a topic that was understood by both of us and taken as such, and perhaps not probed in as much depth as a naïve researcher could have done.

I also work as a community pharmacist and have regular contact with patients taking medication to prevent secondary AMI. In my capacity as pharmacist, I have a professional responsibility to help patients with managing their medication, and also I have insider knowledge of healthcare systems and the philosophical positionality that taking medication is for the benefit of patients, and nonadherent behaviour is in conflict with consensus thought in medicine. I initially found the adjustment from pharmacist to researcher difficult to adapt to when I first presented myself to participants during interviews, but could understand this better when I considered myself as an impartial observer, and tried to reflect this position during interviews.

ii) Interpersonal reflexivity

*What relationships exist and how are they influencing the research and people involved?*

In my relationship to my participants, I acted as researcher, and my profession wasn't disclosed to participants as I didn't want to medicalise the interviews – I was looking for a whole-life view, and also in a role as a pharmacist I had a professional responsibility to promote positive adherence, as opposed to taking a neutral stance as a researcher. The 'School of Pharmacy' features in the University address on the information material, and also in my email signature; a couple of participants assumed that I was a pharmacist, and it was a topic for discussion. I consider that perhaps some participants may have viewed the project differently if it was attached to the 'Department of Psychology'. In my contact with cardiovascular groups, I was aware that the administrative point of contact was a gatekeeper to the participants and I made extra efforts developing good relationships with them, and also that I might become a tea-break topic of conversation in the cardiovascular group might compare their interviews and I would be talked about as 'that researcher girl' (hopefully fondly!). Therefore, care was taken not to disclose other participants, even when they talked about one-another to me, and I tried to make everyone feel like the *star* of their own unique interview. However, it could have been possible that my participants could be influencing prospective participants in the same cardiac support group, which could be both a positive influence to attract them, or could provide them with advance preparation of the types of questioning involved, in the same way that exam candidates share their experience as soon as they've left the room.The anonymity of scientific reporting meant that the identity of the participants is transferred into cases and subsumed into statistics, but every single consenting participant felt like a hard-earned personal success for me, and I was amazed by the generosity of my participants and indebted to everyone for agreeing to take part as I offered no financial remuneration to do so, in the interests of making a fair study.. I was also aware of using the University affiliation and PhD study behind my research as both providing credibility but also a status symbol whereby my research ideas became a concrete PhD project with a gravitas and possibly projected myself as a knowledgeable expert to my participants. Many participants discussed having children and grandchildren at university, with the majority of them being past retirement age, which had influenced their decision to take part and 'help out'. Hence also, by doing telephone interviews, I think they presumed that I was aged in my early twenties and might have responded as though I was closer to being one of their peers, if face-to-face saw that I was in my mid-forties (with a nod to the above imaginary affectionate epithet of 'researcher girl'). I felt it was important to give back to my participants in verbal personal thanks, and also keep them informed of the project outcome so that they could see their involvement and for their own interest. In summary, how I came across to my participants would affect the result I obtained; to them, was I still learning, or was I learned?

In dealing with my supervisory team, I had no knowledge of them prior to this study, and developed familiarity with them through this research. I was aware of their high-ranking roles within the University and outwardly of their high standing within the profession, and was keen that the work produced through this study would be worthy of association with them.

The COVID-19 lockdowns occurred during this research and most of my participants described its effect on their lives and change in availability of interaction with medical professionals. Participants often described how frustrated and isolated they felt during this time, and perhaps felt some catharsis in sharing their problems with me. Working from home and changes of circumstances over the six years of this research made arranging team meetings more difficult.

Through my studies, I found it hard to determine mixing between being proactive, being given the supervisory acknowledgement to work independently and needing to ask for collaboration for validation and supervisory purposes.

iii) Methodological reflexivity

*How are we making methodological decisions and what are their implications?*

The first four interviews were analysed using a phenomenological paradigm, in that we can know the phenomena through a direct first-person experience of it. Four case studies were decided midway through, and the time allocated to analyse and report in sufficient depth was deemed our limiting factor. This study was conducted first also to allow for the data to be analysed with minimal preconceived ideas, and the notion of bracketing the data, for it to be assessed without prejudice. Then the remaining analyses were conducted using data from the first four participants, and eleven further recruits to the study to make a total of fifteen. The next stage of analysis used a constructivist paradigm to build a grounded theory model of participant's experience. This was done following a systematic literature review and so further ideas had been investigated by this stage of the research. Initial ideas about remaining healthy were proposed and avenues iteratively followed, but further analysis determined that the presence of side effects requiring a prescriber change was the final stage in the theory, which was determined after analysis of thirteen participant’s interviews, and confirmed by two additional interviews, that no further categories were generated, and data saturation point was decided.

The narrative analysis was decided following completion of grounded theory analysis, as it showed a prospective fit to our result, which was built using the framework in addition to our result that reflected our findings. The pluralist approach was decided at the initial stages of planning, and the combination of phenomenology, grounded theory and discourse or narrative analysis were decided as complementary paradigms to use, which were reassessed upon each completion stage of studies. The overlaying of the findings of each analysis was difficult to plan as there were few examples in literature, and those found were mostly prose in form, where I was looking to tabulate or visually map my results. There was also a section regarding reflexivity notes following each research analytical stage, which is reported in this thesis following each chapter introduction. These notes were compiled and used as illustrative examples in a pedagogic article written for publication and is currently in review to *Qualitative Methods in Psychology*. Further detail was added following feedback from peer review to the above journal.

### iv) Contextual factors

*How are aspects of the context influencing the research and people involved?*

In the unique situation of this study, participants from central and south of England were involved in interviews, the majority done from their own homes by telephone at chosen times when they were available. Within this context, participants were given the role of expert, as explicitly stated in the opening preamble of the interview, and all interviewed by me, a researcher with medical knowledge and professional expertise in medication management, and interviews were co-created within this social convention of mutual respect and curious discussion based upon a devised interview protocol, and framed with an aim of producing academic research. Participants were often happy to give informal consent to being interviewed over the phone or by email but then were put off at the formal recording of consent stage, which became the limiting factor in their participation. The study design intended on face-to face interviewing, where obtaining paper signatures was not an issue. In the years of the duration of this study, which encompassed the COVID–19 pandemic, societal expectation of online interaction has become normal, and I would incorporate this for future research. However here, access to technology remained a barrier to several prospective participants as they did not have email access or were not able to view or sign documents sent to them by email. Of note also, then we are excluding participants from our study who are not technologically literate, which may impact upon our findings.

## Ethical Considerations

The Code of Ethics of the British Psychological Society were used as a guide to address the ethical concerns of this thesis ((*Code of Ethics and Conduct*, 2018); (Code of Human Research Ethics, 2014)). Ethics Committee approval was given by the University of Reading Ethics Committee (UREC 18/36).

All participants were informed about the study an Information and Consent Sheet, and their permission gained in writing and confirmation verbally at the start of interview. Participants were able to withdraw from the study at any time, up until publication of the study.

All recordings and transcripts will be kept securely at the University of Reading until an appropriate time as decided by the ethics committee.

All participants were adults, and if the main researcher had reason to believe that any participant is a vulnerable adult, they would be politely stopped from further participation in the study.

There was expected to be a minimal risk to participants in this study. The interview was expected to elicit feelings and emotions in the subject no more strongly than would happen if discussed in general conversation. Both participant and researcher are able to stop the interview at any point if they wish to do so.

## Participant Characteristics

A total of fifteen participants were recruited to the study, comprising five women and ten men. Interviews ranged in duration from 17 mins for a pilot interview, the data from which was included in the study, and 69 minutes, with an average time of 47 minutes. Participants ranged from one participant in the 30-40 age group, one in the 50-60 age range, four in the 60-70 range, six in the 70-80 age range, and three participants in the 80-90 range.

Two participants were recruited as a result of the internal University email, and came from the local area to the University of Reading. The remining participants were recruited as a result of contact through cardiovascular support groups, located in central and the south of England.

Participant race, nationality and socioeconomic group were not requested or known to the research team. Participant data was not separated and analysed according to gender as described in the Sex and Gender Equity in Research (SAGER) guidelines (Heidari et al., 2016), as for the IPA study, the reporting was done on a case study basis, and for the grounded theory and narrative analyses, themes were grouped according to similarities and summarised, to work towards generalisability of result, and so the coding was selected for patterns across cases, and looked to an inclusivity across all genders of participants.

# Chapter 3: Literature Review

## Introduction

To place this thesis within the current context for this field of research, a systematic literature review was conducted to determine all published research of qualitative studies of taking medication to prevent secondary AMI. These findings were then collated using meta-synthesis to describe the coverage and content of studies, methods and results.

This literature review will provide a picture of what is currently known about the experience of taking medication for secondary prevention of AMI, and will provide a foundation for the thesis to build upon the current work in this field.

# Paper A: A Systematic Review and Meta-synthesis of Qualitative Studies of Taking Medication for Secondary Prevention of Myocardial Infarction

## Key Questions

What is already known about this subject?

Following an acute myocardial infarction, patients find it difficult to adhere to medication prescribed to improve their long-term health outcomes. Qualitative studies have described the issues around medication-taking from a patient's perspective but are cautious about generalisation outside of their limited cohort to larger post-AMI patient populations.

What does this study add?

This study synthesises qualitative research to find similarities across studies and thus strengthen the argument for applicability, alongside describing the scope of all existing studies, to give a rigorous, detailed picture of our current understanding of medication-taking for this patient group.

How might this impact on clinical practice?

Creating a detailed theoretical model of medication-taking will focus development of more appropriate medication adherence interventions to assist this patient group and therefore improve their clinical outcomes.

## Introduction

Following an acute myocardial infarction (AMI), medical treatment includes adhering to a long-term regime of five medications, risk factor control and lifestyle changes in order to prevent secondary myocardial infarction or further cardiac events (Kotseva et al., 2019). However, patients have difficulty adhering to the regime prescribed, adherence has been measured to be around 60% in this patient group (Naderi et al., 2012), showing a similar pattern across drug classes and further reduces with duration of treatment (Pietrzykowski et al., 2020). Poor adherence leads to increased risk of mortality (Rasmussen et al., 2007) and re-hospitalisation (Ho et al., 2008), which then incurs increased healthcare costs (Bitton et al., 2013).

Qualitative methods are suited to the study of complex social processes and multi-faceted behaviours such as medication-taking, and adherence to prescribed directions. Underused in cardiovascular research, qualitative studies are helpful in defining complex phenomena that are difficult to measure quantitatively and could guide development of a quantitative instrument to measure the effectiveness of an intervention to assist taking medication (McIlvennan et al., 2019).

A Cochrane review of medication adherence found interventions to often be complex and of little effect (Nieuwlaat et al., 2014). Current research in medication is weighted towards quantitative study of arbitrarily chosen interventions. Our systematic review supposes that current intervention design is often without sufficient basis in theory or patient consultation and suggest a ground-up approach to addressing this. A meta-synthesis is the first step in building a rigourous valid theory, in order to better address behaviour change for this patient group (Ye et al., 2012).

The aim of this systematic review and meta-analysis is to investigate the existing qualitative knowledge of medication taking post-AMI and summarise themes that exist across all studies. To date, this is the first systematic review of medication taking in secondary prevention of AMI and makes an important contribution to understanding the issues faced by this patient group to work towards more appropriate interventions to assist these patients in taking their medication.

## Methods

### Protocol

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses, (PRISMA 2020) (Page et al., 2021). As of 7 June 2021, no other systematic reviews of medication taking post-AMI were registered in the Cochrane registry, PROSPERO and JBI registries.

### Databases and Search Strategies

Appropriate search terms were assessed for inclusion by pilot test searching single terms using the PubMed database. A search strategy was developed in collaboration with the School of Pharmacy subject librarian. The strategy for each database was devised and searched using PubMed, Scopus, PsycInfo, Web of Science and the Cochrane Library.

Following the selection of papers, a snowball search was conducted. Using the selected papers, reference lists were searched. The ‘cited by’ function using PubMed was then used for an additional search. The last two searches were repeated on items found using this snowball strategy.

### Inclusion Criteria

The PICOS tool was used to define the inclusion criteria for selected items (Higgins et al., 2019), expressed in Table 3.

Table 3. Study Inclusion Criteria based upon PICOS

| | **Criteria** |
|---|---|
| Population | Adults with diagnosis of myocardial infarction |
| Intervention | Taking medication to prevent further cardiac event |
| Comparison | Experience of taking medication |
| Outcome | (Not relevant here) |
| Study design | Qualitative data originating from patient, not survey or questionnaire |
| Other | Published 2000-2021 (accessible online), in English |

### Study Selection and Data Extraction

The search was conducted by HP and AR individually, and then compared and discussed. The search result data was recorded and organised using EndNote software. The full list of database results and selected citations is provided in Appendix C.

### Quality Assessment

The papers decided for inclusion were then quality assessed by HP and AR individually, and then compared and discussed. The included studies were scored for quality according to COREQ 32-point checklist (Tong et al., 2007).

### Synthesis of Results

The papers were read, and the study characteristic data was extracted from them (Table 4). The main themes found by the authors for each study were then extracted (Table 6).

The most appropriate method of data synthesis was decided upon after completion of the above stages. Meta-synthesis was used to structure and synthesise the findings of the search, chosen because the aim was to answer a specific review question (Thomas & Harden, 2008). Following the meta-synthesis method, the themes extracted from the study were given line-by-line coding, which were then grouped by thematic description, and then analytical themes were generated from the descriptive statements.

The results were presented organised into thematic groups (Table 7). The original papers were then used to add detail back into a prose narrative by theme.

## Results

### Study selection

The database search produced 368 citations, of which 43 duplicates were removed to leave 325 articles for title and abstract screening. This produced 23 eligible articles for full text screening. Following this, 8 articles were included in the review collection.

Snowball searching of references and ‘cited by’ function in PubMed search generated 4 further eligible articles, of which 1 was eligible for full text review, and was subsequently added to the final review collection. The diagram of study selection is shown in Figure 5. The full breakdown of database searches can be found in the Appendix.

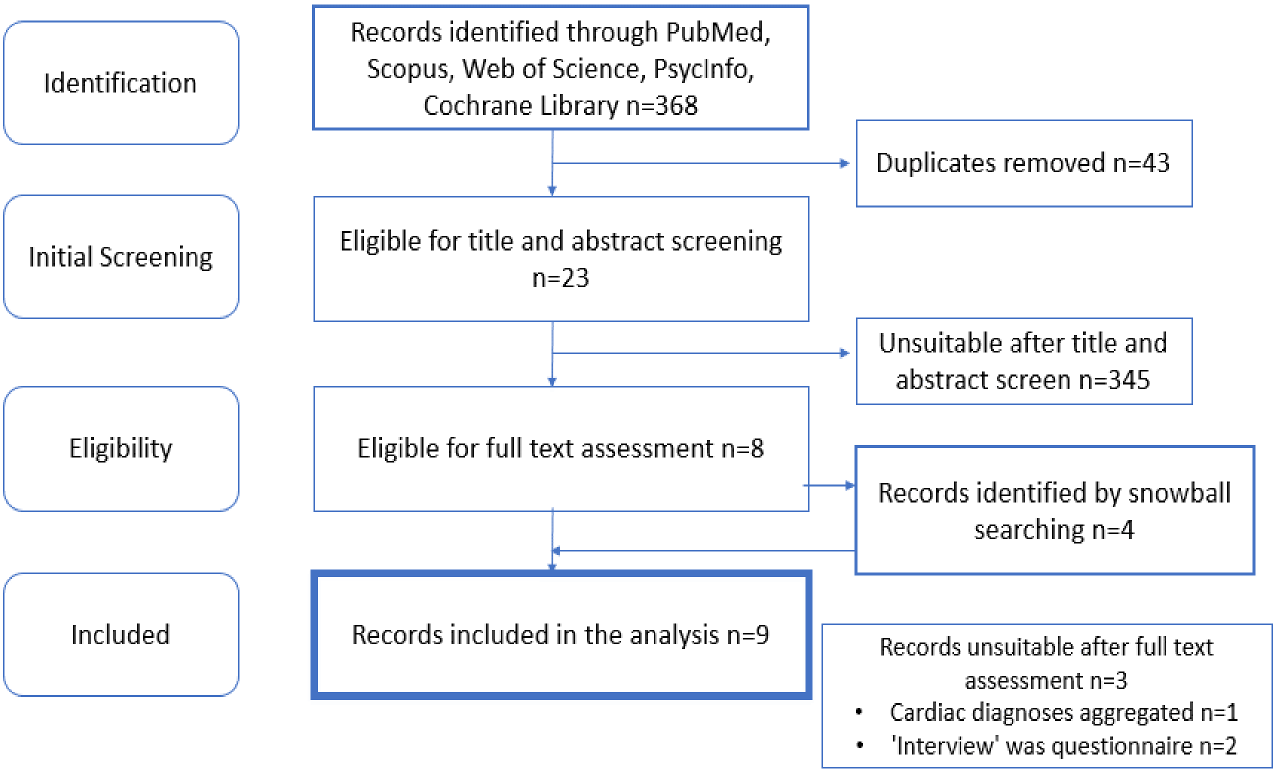

Figure 5. PRISMA Flowchart of the Study Selection Process

Study Characteristics

The included studies dated for 2005 to 2020, with a total sample size of 166 participants, included as individuals, although data suggests that the trio of Garavalia, Garavalia and Decker studies are repurposing their data with sample sizes of 11, 11 and 22.

Table 4. Characteristics of Included Studies

| Authors | Year | Country of Origin | Aim | Design | Methodology | Sample size | Cohort detail | Main Findings |
|---|---|---|---|---|---|---|---|---|
| Attebring MF, Herlitz J, Ekman I. | 2005 | Sweden | To explore patients' experiences of secondary prevention of MI | In depth interview | Hermeneutical analysis | 20 | No previous CVD.<br>12 men, 8 women | Impact of medication-<br>Bodily sensations perceived as due to medicines rather than disease.<br>Impact of health professionals-<br>Communication resulted in confusion about medication and severity of disease. |
| Decker C, Garavalia L, Garavalia B, Spertus JA. | 2008 | USA | To investigate why patients stopped a medication and barriers to adherence | Qualitative interview | Content analysis | 11 | NSTEMI patients with stent. Those who discontinued taking clopidogrel within one month of starting, compared to continuing patients.<br>41-77 years, mostly male and Caucasian. | Discontinuers cited a misunderstanding over treatment duration.<br>Discontinuers also claimed weakness in system, such as gaps in transfer of care. |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Desveaux L, Saragosa M, Russell K, McCleary N, Presseau J, Witteman HO, Schwalm JD, Ivers NM. | 2020 | Canada | Explore the extent, mechanism and future of a behavioural intervention to improve adherence to cardiac rehab and medicine taking | Semi-structured interview | Framework analysis, coding according to Theoretical Domains Framework | 31 | Post -AMI patients given a behavioural intervention booklet. Purposive sample to ensure variance of age, gender, SES, marital status and ethnicity. Separated into not engaged with intervention, engaged with positive outcome, engaged with negative outcome. | Patient's belief about consequences, belief about capability, intentions, social influence and emotions affected their adherence to treatment. The intervention helped patients adhere through reinforcement, behavioural regulation, providing knowledge and social influence. |
| Garavalia L, Garavalia B, Spertus JA, Decker C. | 2009 | USA | Explore reasons for stopping clopidogrel or cholesterol lowering medication in post-AMI patients | Semi-structured interview | Framework analysis, coding according to Health Belief Model | 11 | Post AMI patients, who either discontinued clopidogrel (45-77 years, 18% minority ethnic, 36% female), or cholesterol lowering medication | Cholesterol lowering medication mostly stopped due to side effects, treatment confusion, cost and mistrust of medicines. Clopidogrel stopped mostly due to duration confusion, side effects and cost. |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | n=29 (44-78 years, 19% minority ethnic, 56% female). | |
| Garavalia L, Ho PM, Garavalia B, Foody JM, Kruse H, Spertus JA, Decker C. | 2011 | USA | Describe patient and professional perspectives on why clopidogrel stopped after stent implantation | Semi-structured interview | Content analysis | 22 | Patients with stent following MI, given clopidogrel. Comparison of discontinuers vs. continuers. 45-77 years, mostly male and Caucasian. | Patients perceived lack of knowledge of duration and purpose of clopidogrel treatment. Poor communication between clinicians and clinicians to patient, cost of clopidogrel and poor transfer of care between inpatient to outpatient were stated as barriers. |
| Hanna A, Yael EM, Hadassa L, Iris E, Eugenia N, Lior G, Carmit S, Liora O. | 2019 | Israel | To gain patient perception of health-related adherence behaviours post-AMI | Semi-structured interview | Content analysis | 22 | Patients recruited from a hospital rehab programme, or through community setting, a Jewish Kibbutz and Arab community (20 men, 2 women). | Adherence motivation was facilitated or impinged by inherent factors – willpower, competency and individual preferences. Extrinsic factors were found to be the threat of a recurrent AMI, family and significant others, and healthcare |
| Hilt AD, Mamaqi Kapllani K, Hierck BP, Kemp | 2020 | Netherlands | Understand how patients perceive information provided | Semi-structured interview | Content analysis, patient journey mapping | 12 | Patients (9 men, 3 women), and professionals n=6 (3 | Patients said information provided was too extensive.<br>They perceived medication as a hurdle to recovery, mainly due to side effects, but coupled with an unclear benefit of medication.<br>Their knowledge of anatomy was poor. |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| AC, Albayrak A, Melles M, Schalij MJ, Scherptong RWC | | | to them post AMI. | | | | men, 3 women). Average patient age 62.7 years. STEMI n=10, NSTEMI n=2. | |
| Jalal Z, Antoniou S, Taylor D, Paudyal V, Finlay K, Smith F | 2019 | UK | Investigate beliefs and experiences of CHD and medicine-taking behaviour in post-AMI patients | Mixed methods - (Morisky scale, Belief About Medicines Questionnaire,) semi-structured interview | Framework approach | 13 | South Asian patients attending a London heart attack centre (13 men, 1 woman). 32-72 years. | Most patients perceived medication as important for their health. Half the patients could explain what their medications were for, half relied on family or professionals for this knowledge.<br>Factors that influenced adherence were forgetfulness, family support, side effects, a healthcare practitioner, social deprivation and cardiac rehabilitation. |
| Presseau J, Schwalm JD, Grimshaw JM, Witteman HO, Natarajan MK, Linklater S, Sullivan K, Ivers NM. | 2017 | France | To compare the usefulness of varying behavioural theory based interventions for improving medication adherence in post-AMI patients | Semi structured interview<br>(Questionnaire based upon Likert scale) | Framework approach based upon Theoretical Domains Framework | 24 | Patients contacted at 0-2 weeks, 3-12 weeks, 13-24 weeks and 25-36 weeks post-AMI. | Key factors were beliefs about the consequences of taking medicines, memory, attention or decision processes, behavioural regulation, social role and role of identity. |

## Quality Assessment of the included Studies

The COREQ guidelines 32-point rating of quality assessment can be found in table 5. The scores ranged from 9 (Hilt et al., 2020) to 20 (Garavalia et al., 2009) (Hanna et al., 2020). For the studies that used mixed methods 14, 21, only the qualitative element of the study was used for scoring. The full scoring can be found in Appendix C.

Table 5. COREQ Score Assessment of Included Studies

| Authors | Total + (ex. 32) |
|---|---|
| Attebring et al., (2005) | 16 |
| Decker et al., (2008) | 19 |
| Desveaux et al., (2020) | 18 |
| Garavalia L, Garavalia B et al., (2009) | 20 |
| Garavalia L, Ho et al., (2011) | 18 |
| Hanna et al., (2019) | 20 |
| Hilt et al., (2020) | 9 |
| Jalal et al., (2019) | 18 |
| Presseau et al., (2017) | 14 |

## Themes found in Included Studies

Table 6. Main Themes Found by Authors of Included Studies

| Study Authors | Method of Analysis | Themes Summarised |
|---|---|---|
| Attebring et al., (2005) | Hermeneutical Analysis | Beliefs about consequences |
| | | Memory/ Attention/ Decision processes |
| | | Behavioural regulation |
| | | Social influence |

| | | |
|---|---|---|
| | | |
| | | Social/ Professional role and identity |
| Decker et al., (2008) | Content Analysis | Failure to recognise signs and symptoms of disease |
| | | Seen as not serious |
| | | Believe health is good |
| | | Inaccurate perception |
| | | Denial |
| | | Worsening condition |
| | | Family history/ Fatalism |
| | | Lack of continuity |
| | | Lack of / poor communication |
| | | Inadequate patient education |
| | | Self medicating |
| | | Mistrust |
| | | Side effects |
| | | Unhealthy lifestyle choices |
| | | Economic burden |
| | | Lack of knowledge |
| | | Personal health feelings and beliefs |
| | | Lack of effective communication |
| | | Unaware of cardiac rehabilitation |
| | | Lack of prompts from family and friends |
| | | Missed general cues |
| Desveaux et al., (2020) | Theoretical Domains Framework | Beliefs about capabilities |
| | | Beliefs about consequences (positive outcomes) |
| | | Social influences (pre-existing beliefs) |
| | | Behavioural regulation |
| | | Reinforcement |
| | | Knowledge |
| | | Social influence (having knowledge) |
| | | Beliefs about consequences (negative outcomes) |
| | | Emotion |
| | | Identity |
| | | Memory, attention, decision making |
| Garavalia L, Garavalia B et al., (2009) | Heath Belief Model | Similarities: Cost<br>Side Effects<br>Distrust of Doctors<br>Prescription confusion |
| | | Reduced sense of threat of disease with CLT, higher with clopidogrel |
| | | CLT knowledgeable yet discontinued |
| | | Clopidogrel less knowledge |
| | | Use of 'natural' lifestyle measures in CLT, none reported with clopidogrel |
| | Content Analysis | Lack of knowledge |

| | | |
|---|---|---|
| Garavalia L, Ho et al., (2011) | | Poor communication |
| Hanna et al., (2019) | Content Analysis | Willpower |
| | | A sense of competency |
| | | Personal preferences |
| | | Recurrent event |
| | | Family and relatives |
| | | Healthcare providers |
| Hilt et al., (2020) | Content Analysis | Medicine perceived as a barrier to recovery |
| Jalal et al., (2019) | Content Analysis | Necessity versus concerns |
| | | Knowledge |
| | | Forgetfulness |
| | | Family support |
| | | Side effects |
| | | Relying on health practitioner |
| | | Living in areas of deprivation |
| | | Cardiac rehabilitation |
| Presseau et al., (2017) | Theoretical Domains Framework | Beliefs about consequences |
| | | Memory / Attention / Decision processes |
| | | Behavioural regulation |
| | | Social influence |
| | | Social / Professional role and identity |

Table 7. Study Main Themes Organised by Category

| Study | | | |
|---|---|---|---|
| | Medication Belief | Illness Belief | Adherence Factors |
| Attebring et al., (2005) | Beliefs about consequences | | Memory/ Attention/ Decision processes<br>Behavioural regulation<br>Social influence<br>Social/ Professional role and identity |
| Decker et al., (2008) | Self medicating<br>Mistrust<br>Side effects | Failure to recognise signs and symptoms of disease<br>Seen as not serious<br>Believe health is good<br>Inaccurate perception<br>Denial<br>Worsening condition | Lack of service continuity<br>Lack of / poor communication<br>Inadequate patient education<br>Economic burden<br>Unaware of cardiac rehabilitation |

| | | | |
|---|---|---|---|
| | | Family history/<br>Fatalism<br>Personal health feelings and beliefs | Lack of prompts from family and friends<br>Missed general cues |
| Desveaux et al., (2020) | Beliefs about consequences (positive outcomes)<br>Beliefs about consequences (negative outcomes) | Identity | Beliefs about capabilities<br>Social influences (pre-existing beliefs)<br>Behavioural regulation<br>Reinforcement<br>Knowledge<br>Social influence (having knowledge)<br>Emotion<br>Memory, attention, decision making |
| Garavalia L, Garavalia B et al., (2009) | Side Effects<br>Use of 'natural' lifestyle measures in CLT discontinuers, none reported with clopidogrel discon. | Reduced sense of threat of disease with CLT, higher with clopidogrel | Cost<br>Distrust of Doctors<br>Prescription confusion<br>CLT knowledgeable yet discontinued<br>Clopidogrel less knowledge |
| Garavalia L, Ho et al., (2011) | | | Lack of knowledge<br>Poor communication |
| Hanna et al., (2019) | | Recurrent event | Willpower<br>A sense of competency<br>Personal preferences<br>Family and relatives<br>Healthcare providers |
| Hilt et al., (2020) | Medicine perceived as a barrier to recovery | | |
| Jalal et al., (2019) | Side effects | | Necessity versus concerns<br>Knowledge<br>Forgetfulness |

| | | | |
|---|---|---|---|
| | | | Family support<br>Relying on health practitioner<br>Living in areas of deprivation<br>Cardiac rehabilitation |
| Presseau et al., (2017) | Beliefs about consequences | | Memory / Attention / Decision processes<br>Behavioural regulation<br>Social influence<br>Social / Professional role and identity |

There were three over-arching thematic categories found in all the included studies: beliefs about medication, beliefs about illness, and medication adherence factors.

### Beliefs About Medication

The side effects of medication were described by patients as a bodily effect that needed to be dealt with (Attebring et al., 2005), which is of note, as patients weren’t attributing their symptoms to their cardiac issues. The side effects of cholesterol-lowering medication were painful and interfering with life, and a feature of taking clopidogrel (Garavalia et al., 2009).

Patients discussed that they took medication being to keep healthy (Presseau et al., 2017) and considered not-taking medication as contributing to a shorter life (Desveaux et al., 2020). However, medication was considered to also be a barrier to their health (Decker et al., 2008), the side effects a burden where the benefit of taking was unclear (Hilt et al., 2020).

Patients mentioned a debating process taking place, such as considering medication as an intrusion but also producing feelings of safety (Attebring et al., 2005) and were similarly balancing the necessity versus the concerns over taking medication (Jalal et al., 2019).

Patients who discontinued taking clopidogrel discussed different themes than patients who discontinued cholesterol lowering medication (Garavalia et al., 2009), suggesting that patient experience differs between medication class. Discontinuers of cholesterol lowering drugs didn’t believe they had a cholesterol problem (Garavalia et al., 2009).

In summary, patients described themselves balancing the need to take medication versus their concerns over taking it. They needed to take their medication to remain healthy, to not foreshorten their life, and to feel safe. They were concerned over bodily effects which they deemed to be side effects caused by medication. This burden of side effects, caused pain, intruded into their lives, and was considered a barrier to their health. Some felt the benefit of taking medication was unclear, and were confused by the medication’s link to their diagnosis. Patients who stopped taking one class of medication expressed different beliefs about differing medication classes.

### Belief About Illness

As with medication, patients were negotiating feeling ill versus feeling healthy (Jalal et al., 2019).

Patients varied in their perceived susceptibility to heart disease (Garavalia et al., 2009). In a study of non-adherent patients (Decker et al., 2008), some considered their health status as not serious, and others considered their health to be good. Patients who discontinued taking clopidogrel described their heart disease as serious, this concept was found to be less important for those who discontinued cholesterol reducing medication. Similarly, those discontinuing cholesterol treatment medication believed they did not have a cholesterol problem (Garavalia et al., 2009). When patients considered their illness to be more severe, they used a friend or family member as reference in comparison to their illness (Garavalia et al., 2009).

Another study of non-adherers found they had an inaccurate self-perception, denial of their illness, or a worsening condition (Decker et al., 2008).

The concept of a future recurrent event featured in several studies, as a both a driver to engage in taking medication (Hanna et al., 2020), and concern over having a second heart attack which could be prevented by taking medication (Jalal et al., 2019). There was a reluctance to engage in lifestyle change measures in non-adherers, justifying this by saying that their previous positive health measures hadn’t prevented their first MI (Desveaux et al., 2020).

Family history and fatalism were discussed by non-adherers as heart disease being due to a family history cause, and therefore inevitable (Decker et al., 2008). Similarly non-adherers said that as a result, it was out of their control (Desveaux et al., 2020). Genetic reasons were discussed by the South Asian patient cohort as heart disease being inevitable as it ran in families (Jalal et al., 2019). This group were unique in mentioning the will of god in determining their existential outcome.

One study mentioned the emotional toll of their cardiac illness contributed to depressive symptoms in patients, which became a factor in their non-adherence (Desveaux et al., 2020).

In summary, patients were balancing feeling healthy against feeling ill. Patients discussed the possibility of a recurrent event, which could be prevented by taking medication. They had differing beliefs about their susceptibility to a further myocardial infarction, often non-adherent patients had misunderstood their condition, considering their illness to be not serious or their health good. Non-adherent patients had inaccurate self-perception, a worsening condition or denial of their illness. They didn’t believe their future outcome could be changed by lifestyle measures, and family history determined their future.

Patients who stopped taking cholesterol lowering medication considered their illness to be less serious than the severity of disease considered by those who had stopped taking clopidogrel.

Some patients mentioned becoming depressed following their cardiac event, which affected their medicine-taking.

Patients mentioned ways in which their health was out of their personal control, discussing their genetics, and the will of god.

Medication Adherence Factors

Patients sought out reassurance (Attebring et al., 2005) and support (Hanna et al., 2020) (Jalal et al., 2019) from healthcare practitioners. They discussed that poor communication from professionals was a reason for discontinuation of clopidogrel (Garavalia et al., 2011), and in that study, similarly poor inter-professional communication. Relating to communication, they stated that the transition period following hospital discharge was a precarious time (Attebring et al., 2005) and that receiving conflicting information from professionals added to confusion about treatment and illness severity. Also, discontinuers cited a lack of care continuity, lack of communication and inadequate education as factors in non-continuation of clopidogrel (Decker et al., 2008). The recommendation by healthcare providers was stated as a social influence on adherence (Presseau et al., 2017).

Support from family was given as an extrinsic influence on medication-taking (Hanna et al., 2020) (Jalal et al., 2019), and a lack of prompt from family and friends was discussed as a feature in non-adherers (Decker et al., 2008). Cardiac rehab was also cited as a factor for non-adherers as they were unaware of the existence of a rehab programme (Decker et al., 2008), and cardiac rehab was given as an influence on adherence (Jalal et al., 2019).

Similar to support, patient's adherence was strengthened by having knowledge (Jalal et al., 2019), and lack of knowledge was stated as contributing to non-continuation of clopidogrel (Decker et al., 2008), specifically knowledge about treatment duration and drug purpose (Garavalia et al., 2011).

Memory was seen as a requirement of taking medication (Desveaux et al., 2020), forgetfulness a factor in medicine taking (Jalal et al., 2019), and memory, attention and decision process were cited as determinants of adherence (Presseau et al., 2017). In a similar category was behavioural regulation, where the use of a pill-box was given as an example of an adherence intervention (Presseau et al., 2017).

Patients discussed their belief about their own capability in managing change over a lifetime (Desveaux et al., 2020), discussing the discipline required to maintain medication, exercise and eating habits. That study also cited the consequences and own intentions when reinforced contributed to treatment adherence. Patients discussed willpower, a sense of competency and personal preference as intrinsic factors that influenced their adherence (Hanna et al., 2020).

The incongruence with self-identity was discussed relating to cardiac rehab, where some patients considered themselves to be different to the other rehab patients (Desveaux et al., 2020), seeking their own independent physical activity instead. Social identity was discussed in relation to medication (Presseau et al., 2017) as an action that the patient did not reconcile with their self, ‘taking meds does not fit who I am’. Patients discussed that they felt medication was forced upon them (Attebring et al., 2005).

The economic situation of patients was mentioned as the cost of medication was a barrier to them (Decker et al., 2008) (Jalal et al., 2019), and for both clopidogrel and cholesterol medications (Garavalia et al., 2009). The UK South Asian patient study also found that living in a deprived area affected their medication adherence (Jalal et al., 2019) but did not elicit how.

In summary, medication adherence was helped by the social influence of healthcare professionals. Patients sought support, reassurance and communication from the healthcare team. Patients required information about illness severity and treatment that was consistent between practitioners. The period following hospital discharge was the most difficult time of adjustment. Cardiac rehab was a support to adherence, and the lack of awareness of rehab cited by non-adherent patients. Family was a support to medication adherence, as well as a memory prompt.

Memory, capability, competency, willpower, consequences, knowledge, intentions and personal preference were discussed as important factors in adherence.

Identity was discussed, as patients mentioned the incongruity of their self with being a patient, and themselves to other patients. They felt that medication was forced upon them.

Poverty affected medication adherence, with the cost of medication mentioned as a barrier, as well as living in a deprived area.

## Discussion

The aim of this study was to construct the patient experience of taking medication following an AMI using a meta-synthesis of qualitative studies. This review found that patients discussed their beliefs about illness, beliefs about medication and the factors that influenced their medication adherence.

This meta-analysis provides us with areas that can be further investigated to develop theory and process models in order to assist patients to take their medication correctly to provide the maximum clinical benefit to patients and efficiency to the healthcare system. These themes are important as they provide us with a patient's view of taking medication, experts on this subject by virtue of their practical experience. The aim was to collect all themes associated with the experience. Relationships and processes could be established with further work but are not intended to be defined by this analysis.

All these themes fit within the World Health Organisation's model of medication non-adherence, namely as due to socio-economic, healthcare system related, condition-related, therapy-related and patient-related factors (Sabaté E., 2003). Condition-related and therapy-related directly translate here into illness and medication-related factors. Described under broad medication adherence factors, memory could be attributed under patient related, knowledge and social support traverse healthcare system and socioeconomic groups. More importantly, from the meta-synthesis, the level of detail and specificity found repeated across the literature are the factors that this review adds to our current knowledge.

A notable finding is that taking medication is a reminder for patients of their illness, who are often attributing bodily effects as medication side effects and not associated to underlying health issues. Their perception of their cardiac illness varied, both between patients and within themselves, balancing ideas of their health with their illness. This construct has been found to be important in other studies of adherence to chronic illness medications, where patients are more adherent if their perceived need to take medications is greater than their concern over taking them (Horne et al., 2013). This could be an issue for these patients as they see little effect of the illness, or who are attributing symptoms to medications. However, less is known of necessity versus concerns over long periods of time.

The notion of a possible future recurrence was a driver towards medication-taking, again pushing to the need for a patient to take their medications. The adherence factors that patients discussed included knowledge, memory and social support from both family and professionals. These are important because they are tangible psychosocial factors that can be addressed using behaviour change techniques in order to support patients.

Whilst fulfilling the inclusion criteria, the study aims were often not always the same as the aim of this review, and so it is worthwhile to mention epistemological positions to show the coverage of studies included (Greenhalgh et al., 2005). Those closest together in theoretical paradigm were the Attebring et al., Hanna et al., Jalal et al., and Presseau et al. studies, as the aim of these studies was to describe the experience of medication taking in this group of patients. The Desveaux et al. and Hilt et al. studies assessed the experience following an intervention of support via phone discussion and a support booklet respectively. In the trio of Decker, Garavalia et al., Garavalia, Garavalia et al., and Garavalia, Ho et al. studies, all patients had received surgery and stent insertion as a result of their MI, and this was the context of their research, whilst still fitting within the search criteria of this analysis. They also appear to have used data from the same cohort of patients, showing similar numbers and age range, perhaps limiting the scope of their results. The Desveaux et al. and Presseau et al. studies used the Theoretical

Domains Framework to organise the themes of their studies, and so the results were already ordered within a higher order category than the primary interpretation of results that were presented in all the other literature.

The diversity of result within the meta-analysis could be further examined, as a reflection upon the generalisability of the findings. A total of 124 patients were included in this review (counting the Garavalia trio as a total of 22), spread across multiple locations in the world, however being limited to English studies meant a tendency towards studies from European and colonial nations. There was a bias towards male participants overall, and only Desveaux et al. mention purposive sampling in order to balance ethnicity and socio-economic status.

Scientific rigour and quality assessment was implied from the literature included, as they were taken from published peer-reviewed journals. A further assessment of quality was done using COREQ scoring, again a validated and reliable instrument for quality assessment. As the Jalal et al., and Presseau et al. studies also contained a quantitative element to their study, only the relevant qualitative data parts were extracted for the purpose of this study. The nine studies found were of varying scored quality, but those deemed to score lowest, the Hilt et al. study also only contributed two themes to the results and which had already been generated in other studies, and so the concern for giving greater significance to results with less reliable data is reduced. This is a concern in an article that called out for sensitivity analyses in order to decide how the inclusion or exclusion of differing quality studies affected the final analytic themes (Dixon-Woods et al., 2016). The same finding was discussed by another study, where their study of the poorest quality contributed minimally to the result (Thomas & Harden, 2008). However, scoring shouldn’t be used as a judge of quality, as the domains don’t carry equal weight, a score gives a false sense of precision, and the cut-off points are arbitrary (Noyes et al., 2018).

All patients had engaged with the health provision, then stopped, which are classified as intentional non-adherers and may be a different type of patient than those who don’t engage with health services from the outset (Hugtenburg et al., 2013). It is of interest that these studies found differences in themes between continuing and discontinuing patients, implying that discontinuers discussed barriers, whereas continuers mentioned barriers alongside ways in which they overcame them. They also found reporting of themes differed between those that discontinued clopidogrel and those that stopped cholesterol medication. This indicated that the construct of the phenomena could be different between these patients. Again, the emphasis that there is no inference of causality at this stage of the review.

There are two literature studies that this research builds upon. One study was a systematic review of all qualitative literature on medication adherence (Mohammed et al., 2016), which investigated the patient lived experience of medication, and found three themes, the medication-related burden, medication-related beliefs, which then fed into medication-related practices. Their study used theoretical domains theory as the framework with which to organise their data. There is a clear overlap of medication-related beliefs and illness related beliefs in this study and factors that influence adherence. Similarly, all the themes extracted in our meta synthesis could be translated into theoretical domains, but with a resultant loss of detail. It is the specifics contained within this study’s findings that make it of interest, and to our knowledge, no other similar systematic reviews have been conducted exclusively with myocardial infarction patients regarding their medication taking practice.

Another literature review was done to study the secondary prevention medication taking behaviour of coronary heart disease patients (Rashid et al., 2014), which concluded that behaviour was a result of medication related beliefs and disease related beliefs, and these themes came about as a result of clinician relationships, pre-existing health beliefs, their socioeconomic and cultural environment, interaction with health system and influence of partner and family. Their study included four studies that were also used within this study, another reassurance of cross-checking the search result. However, it included three studies that were not found in the present systematic search. They included a study which referred to the participants as CHD patients (Kärner et al., 2002), and discussed their construct of the disease and treatment, which did not fulfill the inclusion criteria for our meta-synthesis. Similarly, another studied the experiences and needs of patients (Webster et al., 2002), and so similarly would have been excluded due to not expressly stating medication experiences. Of interest is that this is a study of a Gujarati Hindu cohort, and one of the findings was a significant belief in fate and the will of god, overlapping with that of the Jalal et al. study included here.

There is an argument for using more specific patient group than that of coronary artery disease, and coronary heart disease, as they have included patients that the disease related beliefs may present differently for if no acute event has taken place as with AMI. The results again resonate with the findings of this study, with the exception that they appeared to place a greater emphasis on fatalism discussed within their results, and patients thinking that an intervention had cured them, which was not mentioned in any of the studies found in this literature search.

The authors of this review have completed a phenomenological study that would have been included in this search, which was pending publication at the time (Piekarz et al, 2021). Our study found that patients discussed the assimilation of medication into their lifestyle, knowledge and disruption to routine, which link to adherence factors in this review. We found that patients considered the future, and compared themselves to others, which links to illness beliefs in this review. In our research, we did attribute any themes into a medication belief category. Instead, we classified themes such as side effects into the assimilation into lifestyle group, which shows that not only the groups are fluid and open to interpretation but suggests that themed groups are linked by a process. The belief about medication and illness are perhaps pre-experience knowledge, and then get rejected or strengthened through experience, and go onto to become incorporated into lifestyle through practical adjustment.

By using a cohort of similarly diagnosed patients, the aim is to tailor the result as close as possible to their own personal journey. It could be argued that within the AMI group the type of diagnosis confers a dissimilar experience, and further study could compare STEMI and NSEMI patients.

By summarising the themes by meta-synthesis, the qualitative result across studies increases in value in terms of generalisability, as findings of similar themes have become grouped, and more in-depth detailed points have been extracted. The third order new synthesised findings have been rigourously checked for quality and validity. However, it remains that the results form a contemporary picture of the phenomena and make no claim to prediction of future events. They are useful as a guide to direct current work, and a starting point for developing interventions, and further direction for theory development.

## Conclusion

This systematic review and meta-synthesis of medication taking to prevent a further AMI has found that patients discussed beliefs relating to medication and their illness, and also described medication adherence factors that supported them including family and professional help, knowledge, and their own memory and capability. This result provides researchers with themes for further investigation into process and theory building.

The absence of themes also is grounds for further study, such as the broader cardiovascular patient group discussed that they stopped medication as they mistakenly thought their treatment had ended, which was not found to be the case within this patient group.

## Summary of Findings and Discussion

Following this systematic review, the details discussed above have shown that patients discussed beliefs relating to their medication, illness, and how they are supported by family and healthcare professionals, their own knowledge and routine-building capability.

This review also shows that no prior study as proposed by this research has taken place, and also that the selection criteria produced nine studies, which were specific and limited in their scope, often fulfilling the search criteria by virtue of one element in a specific study whose aim was not to fulfill an outcome relating to the search for improved adherence. There is a general lack of qualitative research in this field, and also research at the level of searching for factors that affected medication adherence. The total quantity of nine studies found illustrates the lack of evidence for the basis of quantitative studies, which are arguably based upon presumed factors guided by more general medication adherence research, which may not necessarily apply to this secondary prevention of AMI patient group. Therefore further qualitative investigation of factors involved in the experience of taking medication for this patient group is warranted.

# Chapter 4: Phenomenological Analysis

## Introduction

As described earlier, this study is chronologically the first research project of this thesis, in order to analyse the data with a close first-person perspective that involves bracketing around the concepts discussed by the participant, and that isn't subject to previously informed ideas.
On reflection, it was also appropriate to start with a method of analysis that used a well-established framework that was suited to a novice qualitative researcher. This framework was adapted to include further categories of time, location, embodiment and relationships, which assisted which the organisation of data.  Four case studies were chosen to allow the research resources, mostly time, to be allocated and allow for sufficient depth of analysis to take place.

## Reflexivity

As an introduction to my research, this was a great methodology to start with, as it followed an interpretative framework, so removed some of the pressure in being 'correct' in terms of formal analysis, and my confidence and practical analytical skills developed following each participant's case. The first interview was a pilot to reflect upon the interview schedule, but the data from this was considered sufficient to be included as whole case study due to the coverage and depth obtained within the short duration of interview. As I progressed, I also built my questioning skills to draw out the points that participants touched upon, using notes to write them down and ask later, and also to naturally adapt my line of questioning to fit these into the interview progression. The first two cases I worked in close collaboration with my project supervisor, and worked a line-by-line analysis together, which affirmed that our understanding of the analysis was similar, and verification that the framework was being followed. I was content to continue to check back periodically to share findings, and we proceeded to work together, but with less simultaneous analysis. I was boosted by the trust that was granted to me to continue working in this way. By recruiting participants from within the University to begin with, I found it less daunting an introduction to the administration and interview process than it would have been if I'd immediately ‘gone public’ with my recruitment. I felt that it was easy to build a rapport with these participants having some connection either locally or within the University to talk about. During these interviews I was still learning to *not* be a healthcare professional, and signposting and deflecting statements that could be seen as requests for advice. I was taken with how helpful and cheery these participants were, and how their personalities came across through both recollections and style of their talking.~~.~~

# Paper B: A Phenomenological Analysis of the Experience of Taking Medication to Prevent a Further Heart Attack

## Abstract

*Background* Following an acute myocardial infarction, patients are prescribed a regime of cardio-protective medication to prevent recurrent cardiovascular events and mortality. Adherence to medication is poor in this patient group, and not fully understood. Current interventions have made limited improvements but are based upon presumed principles. *Aim* To describe the phenomenon of medicine-taking for an individual taking medication for secondary prevention for an AMI. *Method* Interpretative Phenomenological Analysis was used to analyse transcripts of semi-structured interviews with participants. Themes were generated for each participant, then summarised across participants. *Results* Five key themes were produced; the participants needed to compare themselves to others, showed that knowledge of their medicines was important to them, discussed how the future was an unknown entity for them, had assimilated their medicines into their lives, and expressed how an upset to their routine reduced their ability to take medication. *Conclusion* Participants described complex factors and personal adaptations to taking their medication. This suggests that a patient-centred approach is appropriate for adherence work, and these themes could inform clinical practice to better support patients in their medicine adherence.

Keywords

Acute Myocardial infarction; Interpretative phenomenological analysis; Medicine adherence; Patient experience; Patient-centred care; Semi-structured interview

## Introduction

Cardiovascular disease currently causes over 4 million deaths annually in Europe (Townsend et al., 2016). Acute myocardial infarction (AMI) is responsible for the largest proportion of these, estimated to be 15% of the total (Chadwick Jayaraj et al., 2019). In the UK, just under one million people are thought to be AMI survivors (Bhatnagar et al., 2015).

Following an AMI, a combination of five different classes of medicines are recommended as part of treatment guidelines for secondary prevention in the UK (Jones et al., 2013), the US (S. C. Smith et al., 2011), and Europe(Graham et al., 2007). A meta-analysis of these drug groups has found that following the five-drug therapy confers a 40% reduction in mortality and 25% reduction in cardiovascular events (Ma et al., 2019)(Ma et al., 2019). Whilst a broader study in coronary heart disease patients, it found that the reduction in all-cause mortality and cardiovascular events was due to an additive effect. This highlights the importance of taking these drugs in accordance with the prescription issued by a health professional.

Medicine adherence is defined as “the extent to which a patient’s behaviour matches agreed recommendations from the prescriber” (Nunes, V, Neilson, J, O’Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009)(Nunes, V, Neilson, J, O’Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009). Meta-analytic data from 376,162 patients has shown the level of adherence in patients taking medicines for secondary prevention of AMI to be 66% (Naderi et al., 2012). This study found no other statistically significant differences between the drug classes, which suggests that non-adherence is not related to a drug class characteristic, such as a drug side-effect, but to other factors. Because non-adherence in AMI increases one-year mortality, hospitalisations and costs (Baroletti & Dell’Orfano, 2010), it follows that improving medicine adherence should then reduce patient mortality, morbidity and healthcare system costs.

Improving medicine adherence has been a focus for the World Health Organsation (WHO) (Sabaté E., 2003), which famously reported that “increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments”.

In the UK, the standards of practice for the NHS are determined by the National Institute for Health and Care Excellence (NICE), which has produced treatment guidelines for improving medicine adherence (Nunes, V, Neilson, J, O’Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009). This report acknowledges the need to understand patient perceptions of their medicine along with the physical practical support that can be given to aid patient adherence. It recommends that adherence is supported through patient involvement in decision-making, offering information, and being aware of patient concerns.

There has been much research into finding effective interventions, yet many are complicated and eventually unsuccessful in terms of improving medicine adherence and clinical outcomes (Nieuwlaat et al., 2014). Most adherence research uses quantitative methods to determine adherence as an outcome, with a thin evidence base underpinning the theoretical framework. A study of the data from adherence studies concluded that most interventions are not produced as a result of theoretical models (Van Dulmen et al., 2007), even though interventions aimed at changing behaviour have been shown to be more effective when based upon theoretical models (Abraham et al., 2009). Therefore, a qualitative approach would be useful to generate themes and propose models which could ratify conceptual frameworks and direct further work in quantitative studies. Historically, there is a lack of qualitative research into medicine adherence (Vermeire et al., 2001)(Vermeire et al., 2001).

Consistent with a patient-centred approach, a qualitative phenomenological study is appropriate to obtain a patient perspective of the experience of taking medicines, beliefs, and how patients conceptualise their medicines within their lives (F. Smith, 1998). In addition, a study that includes an exploration of the social context and lived world of a patient would be appropriate, and an ethnographic patient interview is suited to this purpose (Rosenfeld & Weinberg, 2012).

Interpretative phenomenological analysis (IPA) was chosen as an established accessible methodological framework upon which to base this study (Pietkiewicz & Smith, 2012). There is debate between the leading practitioners in phenomenology as to the philosophical underpinnings of their own respective methods (Zahavi, 2019) . In order to develop a deeper phenomenological aspect to this study, the additional framework of existential life-world categories of time, location, embodiment and relationships were used in the analysis (Madjar, 2014).

## Aim of the Study

To describe the experience of an individual taking medication to prevent a further AMI, and factors that influence their medicine-taking ability.

## Ethics Approval

This study was approved by the University of Reading Ethics Committee (Reference UREC18/36).

## Method

This study followed COREQ guidelines to conduct the research (Tong et al., 2007). A sample size of four participants was chosen to enable a quality analysis to take place, to ensure thoroughness, depth and maintain ideography of the analysis, consistent with an Interpretative Phenomenological Analysis (IPA) study (J. A. Smith et al., 2009)(J. A. Smith et al., 2009).

Participants were recruited using a promotional poster cascaded by email within the University of Reading, which was also sent to targeted cardiac support groups within the locality of the South-East region of the UK. The criteria for inclusion were adult individuals with a diagnosis of AMI and who had been prescribed medication for secondary prevention of AMI.

Initial contact was made through email with the first author, HP, the study information was distributed, and written consent returned in person or via email. Prior to interview, participants were assigned a pseudonym. All participants who made initial contact followed through to full interview.

All interviews were conducted by HP in a private office room, either face to face or over the telephone, between June 2019 and January 2020. The interviews ranged in duration from 17 minutes to 65 minutes, and average time of 48 minutes.

A semi-structured interview schedule was used to guide the interviews. The schedule was informed by one used in a similar medicine adherence phenomenological study (Rathbone, n.d.), and more general literature on developing interview protocol (Kallio et al., 2016). Following the first interview, the schedule was refined in accordance with a self-reflective ‘interview the interviewer’ technique (Prescott, 2011), the final schedule can be found in Additional Information. All listed questions were put to the participants, and during the interview, further lines of questioning and probes were added in response to answers given by the participant as the interview progressed.

Field notes were taken by HP during the interviews as an aid to topic coverage. Immediately following the interview, notes were made on meaning of discussion topics, to aid in the analysis. The notebook was used during the transcription and analysis stages also, to add a reflexive commentary on the researcher’s thoughts and sense-making process.

Interviews were audio-recorded to MP3 file, which was transcribed verbatim by HP into an MS Word text document. The transcripts were checked alongside the audio to confirm accuracy. In line with a transparent study, participants were sent a copy of their transcript. No participants disagreed with the content of their transcript.

Analysis was undertaken according to IPA (J. A. Smith et al., 2009). All transcripts were analysed by HP, a novice qualitative researcher, PhD student and practicing pharmacist. The transcripts were read a minimum of twice, and line-by-line notes made using an IPA stance, a description of the meaning and understanding by the researcher of the participant’s statements.

The first transcript notes were discussed with PD, an experienced qualitative researcher and Professor of pharmacy practice, with specialisms in anthropology and psychology. This discussion generated further notes, consistent with a “mini-independent audit” (J. A. Smith et al., 2009), a check of validity. This discussion of notes was repeated for the second transcript.

Life-world framework categories of time, location, embodiment and relationships were used as an initial means of organising and arranging the notes (Van Manen, 2016). The transcript notes were colour-highlighted by life-world category and grouped.

Following the first sift into lifeworld groups, the transcript notes were coded into thematic groups, collected together according to concept. These groups were used to write a participant summary document in prose, which described each individual, arranged by life-world category. In line with IPA, preservation of the participant’s voice is important, and so the original interview quotes were used to illustrate themes. Analysis was repeated for each transcript and a summary document was produced for each participant.

The summaries of themes for each participant were grouped together, using overarching themes that encompassed all the concepts encoded in the themes that they described. These were the superordinate themes that featured across all the participants’ transcripts. These superordinate themes were organised into tables illustrated with the original text quotes from each participant which are presented in the results section below.

## Results

The participants (n=4, 2 women, 2 men) were assigned the pseudonyms Gaye (Table 8), Beki (Table 9), Chris (Table 10), and Colin (Table 11). They all described their AMI as a “heart attack” and so this term is used henceforth. All participants were white, British, lived in the South-East region of the UK and came from higher professional or business-owner backgrounds in their working career. They all initially received emergency care through the NHS and continued their access to healthcare through their NHS general practitioner service. Beki and Chris sought additional care through using private consultant cardiologists.

Gaye is a retired woman, in the age range 60-70 years. She had two heart attacks and considers that her healthy vegetarian lifestyle is the reason that she survived them. She had difficulty swallowing tablets but overcame this by taking her medicines simultaneously with swallowing a grape.

Beki is a working woman in the age range 30-40 years. She had two heart attacks but considers herself an anomaly due to her fitness and young age. Her initial diagnosis was not of a heart attack, it was through her own research that she found a consultant to confirm a diagnosis of heart attack.

Chris is a retired man in the age range 60-70 years. He had one heart attack. He decants all his medication into a Tupperware box in order to save time and hassle. He also takes medication for back pain and restless leg syndrome, for which he adjusts doses according to the severity of his symptoms.

Colin is a retired man in the age range 60-70 years. He had one heart attack, whilst on the golf course and was air-lifted to hospital away from home. Dissatisfied with the quality of transfer of his care between hospital and GP, he sought private healthcare.

The participants discussed medicine-taking through four superordinate themes (Table 12); they *compared themselves* to others, *knowledge* was important to them, they considered the *future* in some form, and they discussed ways that they fitted their *medicines into their lifestyle*. A related theme to lifestyle, all participants discussed how *a change to their routine* adversely affected their medicine-taking.

## Comparison to Others

One of the superordinate themes was the way in which participants focussed on their history and lifestyle leading up to their heart attack in reference to other people, often evidencing that they were in a superior position, and as proof that their body was healthier by managing to survive the heart attack.

This theme was interpreted as participants constructed a ‘typical’ heart attack patient profile for comparison in terms of healthy living status, gender, age and type of heart attack. For example, terms like “Didn't fit the bill for anyone having a heart attack”, and “I’m not your fat sixty or seventy year-old man”.

They frequently gave examples of how they were health conscious. They considered that vegetarianism, non-smoking, training for a marathon, preparing for pregnancy, and gym attendance to be attributes that made their health superior. They used their own biometric results to compare their health to normal ranges as justification that their health is comparable to ‘normal’. They also described similar diagnoses in acquaintances, friends and relatives to discuss how their case was different, with the implication that their case was less morbid. Colin defined himself in terms of luck.

### Knowledge

The superordinate theme of knowledge encompassed a range of themes that included questioning the cause of their heart attack and need of their medicines, seeking information, having a theoretical and practical knowledge of their medicines, sharing information with others and receiving support as part of a group. The category of knowledge also encompassed self-perception, including participants' understanding of their own medical status, fitness, and medication. The concept of having knowledge was interpreted as an understanding of their body helped participants to regain control over it. Participants commented they “Read the leaflet about what they do and what the side effects are" and asked, "Are they doing what they're supposed to?"

All participants were able to describe their medicines and medical treatments. In addition, they showed curiosity to know about their treatment, either finding answers themselves or using the knowledge of others. Gaye articulated her lack of knowledge about her medicines.

All the participants could recall the names, timings and strengths of their medicines, often referring to paper copies of medical notes during their interview, although these were not requested by the researcher. They found information through hospital consultants, GPs, acquaintances, family, support group and rehab group members. They used sources such as medicine information leaflets and academic-level databases. Two participants sought the knowledge of a private consultant, reasoning that the consultants' professional status conferred a better level of care. One participant linked private healthcare with receiving better care and economic status.

### Considering the Future

This superordinate theme was drawn out by participants as they invoked the idea of the future in all their narratives. This theme was interpreted as constructing certainty and reassurance. The uncertainty of the future illustrated by "not knowing where I was heading". Gaye, Beki and Colin all mentioned taking medicines continuously into the future, using an almost identical phraseology of "having to take these forever", and Beki's "every day for the rest of my life".

Gaye mentioned that the future is unknown in terms of heart health, and Beki considered that another heart attack is possible. Colin used the future conditional tense as he talked about having taken his medicine for such a long time "it had built up inside", and that if he missed a dose, it "shouldn't be a problem".

## Assimilation into Lifestyle

Another broad superordinate theme was assimilation of medication into the participants' lives. All participants relayed how they accommodate their medicines into their everyday routine in a unique way. This group included themes of personal relationships, medicine location, systems and adaptations. This theme was interpreted as fitting medicine-taking to their life-world, a means of control and stability. They used phrases such as "Take them when it fits me", and "It's just a routine now".

Gaye and Colin discussed being overwhelmed initially, but then how taking medication has become part of their everyday life. They both described the routine they had created, now as unremarkable and not noticeable. Both Beki and Chris mentioned a difficulty, Beki because of the side-effect, and Chris because of the extra quantity to remember, but they persisted with their set treatment.

Gaye began with swallowing difficulties but was given a "tip" by a pharmacist, and now takes medications simultaneously with a grape.

The location of medication was discussed as a practical decision or based upon their beliefs. Beki sites her medication in her kitchen, "out of the way" as her son's safety is a priority. Chris decants all packaging and keeps them mixed in a Tupperware box, as an efficiency measure. Colin keeps his medication in a pouch which remains in one location at home, his GTN spray is the only item that he will carry in his pocket whilst at the gym.

Beki discussed how her pregnancy took priority over her medicine taking, as she stopped taking some of her medicines.

Chris and Colin talked about medicine-taking as an effortless activity, both using the analogy of coffee and tea-drinking to describe the automatic nature of taking medicines. Chris compared cultural drinking to taking different medicines, “coffee for that, wine for this”.

Neither Chris and Colin were concerned about missing doses, Chris reasoning that missing medicines wasn’t life-threatening, and Colin because he doesn’t notice any difference.

### Disturbance to Routine

All the participants discussed how a disturbance to their daily routine could result in their missing a dose of medication. Disturbances included being away from home, being on holiday, and distraction by another activity. In opposition to the previous theme, this was interpreted as a destabilisation of their habitual activity. They described “The routine is a bit different” and saying, “I went to bed and forgot that I'd not taken my pills”.

Being away from home was discussed as a reason by all participants. Gaye talked about going out and forgetting her evening dose of statin. Beki suggested that she might be out and forget to take a dose. Chris took his medicine box out with him to ensure he did not miss doses.

Colin’s wife gave him verbal reminders when away on holiday and he mentioned different time zones causing confusion.

Chris gave the example of being absorbed on the internet and so went to bed without taking the evening dose. Colin discussed missing doses when his family came to stay at his home.

Table 8. Summarised Themes and Example Interview Quotes from Gaye

| Superordinate Theme | Theme | Quote | Transcript Line Reference |
|---|---|---|---|
| Comparison to others | Health conscious | Lifelong vegetarian<br>Never taken medication<br>...Because I was living that lifestyle (Re: survival)<br>As fit as a butcher’s dog | 44<br>65<br>152<br>169 |
| | Unusual case | Didn't fit the bill for anyone having a heart attack<br>Didn’t fit anyone’s profile | 43<br>48 |
| Knowledge | Medicine information | Medicine names, dosage and times | 77, 79 |
| | Question cause | Why had it happened, | 146 |
| | Question medicines | Are they doing what they’re supposed to?<br>What would happen if I didn’t take them?<br>How does the combination work? | 219<br>220<br>234 |
| | Self- Perception (Medicines) | Am I on the highest?<br>Am I on the lowest? | 224 |
| | Self- Perception (Fitness) | No idea of what level you’re at | 176 |
| | Sharing knowledge | I told her what I'd been told | 187 |
| | Strength in numbers | Collective support (re: rehab group) | 234 |
| Considering the Future | Planning into the future | To be seen in a couple of years | 172 |
| | Indefinite | Continue to have to take these | 241 |
| | Continuous future | Forever and being compliant | 242 |
| | Unknown future | Not knowing where I was heading... | 152 |
| Assimilation into lifestyle | Overwhelmed initially | Started off with a whole raft of things | 52 |
| | Physical issue | Could never swallow medicines | 92 |
| | Overcome issue | Always have to have grapes | 113 |
| | Taking medicine is unremarkable | It’s just a routine now | 107 |
| Disturbance to Routine | Being away from home | Can be a bit difficult when you’re travelling | 113 |
| | Distracted by activity | Been a particularly busy day, it’s not until | 109 |

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| | | the evening when I thought, ‘Crickey!’ | |

Table 9.Summarised Themes and Example Interview Quotes from Beki

| Superordinate Theme | Theme | Quote | Transcript Line Reference |
|---|---|---|---|
| Comparison to others | Health conscious | Training for the marathon<br>Planning on starting a family<br>Never smoked<br>Been this weight since...a teenager | 5<br>137<br>259<br>558 |
| | Unusual case | I’m not kind of, your normal case<br>The youngest person on the cardiac ward<br>I’m not your fat sixty or seventy year-old man<br>My heart function is normal<br>My heart has no damage to it | 628<br>607<br>95<br>456<br>458 |
| | Dislike of labelling | I hate that term (re: saying I have heart disease) | 448 |
| Knowledge | Medicines information | Medicine names, dosages, timings | 77, 78,79, 159, 190, 192, 222, 246, 248 |
| | Self-perception (Medical) | Cholesterol...high for me<br>All of the data | 256<br>116 |
| | Seeking information | Load of Googling<br>A bit of PubMed searching<br>A UK Facebook group<br>A lot of my friends are Doctors<br>Spoke to a friend... endocrinologist<br>Sister-in-law is a consultant | 422<br>656<br>427<br>696<br>657<br>734 |
| | Cynical of care | They were generally a bit rubbish<br>The ECG technician will answer your question<br>Here's a bag of stuff<br>A whole leaflet of aftercare | 99<br>105<br>293<br>296<br>976,977 |

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| | | The woman that hands me... probably has no clue | |
| Considering the Future | Future unknown | Try not to dwell, may happen again | 461,462 |
| | Continuous future | Every day for the rest of my life (re: taking medicine) | 344 |
| | Planning ahead | Lipids done every year<br>Making an appointment<br>Four medicines every six weeks | 964<br>622<br>648 |
| Assimilation into lifestyle | Consistent location | They're all in the kitchen<br>Down in the kitchen | 477<br>375 |
| | Reason for location | Out of the way<br>Aspirin has to go in water | 478<br>374 |
| | Child is priority | Had stopped taking the (contraceptive) pill<br>Came off statin, clopidogrel<br>Breastfed him<br>A break while I was pregnant | 156<br>177<br>186<br>971 |
| | Concern for partner’s anxiety | Look like a battered wife (re: bruising as side effect)<br>My poor husband... woke up, thought I was dead (re: coldness as side effect)<br>I think my husband worries about it more than I do | 902<br>141<br>142<br>442 |
| | Side effect tolerated | For the sake of a year, it’s fine (re: clopidogrel causing bruising) | 921 |
| | Side effect unacceptable | Felt like wading through treacle | 138 |
| Disturbance to Routine | Being away from home | I think probably I was out and thought, ‘oh yeah’. | 492, 494 |
| | Distracted by activity | Just didn’t ’cause I came home and went straight up to bed | 495 |

Table 10.Summarised Themes and Example Interview Quotes from Chris

| Superordinate Theme | Theme | Quote | Transcript Line Reference |
|---|---|---|---|
| Comparison to others | Parallel self | That was the heart attack that would have been fatal | 52 |
| | | And er, if we hadn’t gone – who knows? | 85 |
| | | Thinking - I've got cancer | 523 |
| | Comparison to an acquaintance | You know, just passed away on the spot | 66 |
| | Comparison to relatives | I have two brothers. Both younger. | 942 |
| | | He had a triple. | 944 |
| | | He needed a bypass, but because of his head (re: other brother has pacemaker) | 949 |
| | | We do compare notes between us | 968 |
| | Unusual case | My heart was undamaged | 926 |
| | | My heart had found ways of getting supplies from other channels | 924 |
| | | It was a re-plumbing job - it wasn’t a heart repair job, which I think was quite significant | 936, 937, 938 |
| Knowledge | Medicines information | Names, doses, times and identification of medicines | 169, 182, 183, 194, 195, 196, 223,273, 284,285, 286,474 |
| | Theoretical knowledge | And also one used for epileptics | 180 |
| | | Which is again, a drug normally used for Parkinson’s disease | 190 |
| | Practical knowledge | Intelligently, I have, you know (re: self-adjusts dose) | 558 |
| | | Self-diagnosed, self-prescribed | 500 |
| | | Did off my own back | 563 |
| | Follows advice of professionals | I’ll stick with that one | 581 |
| | | Wouldn't stop taking that one without taking advice | 582 |
| | | ‘Cause it helps with the heart rate | 579 |
| | | If that’s what they say, I won’t question | 976<br>979 |

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| | Self-perception (Medicine) | I'm on about as low as you can get | 575 |
| | Self-perception (Medical) | My readings seem to come out OK | 218 |
| Assimilation into lifestyle | Continuing as usual | And I'm taking it when it fits in with my life<br>Just throw in the morning 'cos it's more convenient to me<br>Take them when it fits me | 205<br>217<br>227 |
| | Adapting to change in routine | And I get on with it 'cos it's only short-term (re: antibiotic course)<br>I'd probably do one of those for the flight time (re: small pill box)<br>It lived in the car all day...Wanted to make sure I had the afternoon ropinirole with me | 340<br>357<br>368/370 |
| | Taking medicines is unremarkable | Sort of, pick them up, chuck them in and swallow them<br>And taken without thinking<br>It's whatever's in front of me<br>Like having a cup of coffee or a glass of wine (analogy: routine)<br>Coffee for that, wine for this (analogy: cultural) | 297<br>113<br>292<br>535<br>1092 |
| | Location of medicine | This square box with a green lid that's got everything in<br>Sometimes it's in the kitchen<br>Sometimes the worktop, sometimes the cupboard | 361<br>364<br>365 |
| | Constructed relationship with regular medicines | My normal, you know, cocktail<br>A routine, daily medicines, wall to wall<br>Doesn't become a part of the family of the rest in my box (re: antibiotics)<br>It's a bit of an intruder | 343<br>1023<br>336/337<br>339 |
| | Made own system | Works absolutely brilliantly | 361 |

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| | | That's my method<br>Sorry, but that's the way I do it | 389<br>391 |
| | Concern for efficiency | A tenth of the time it would the other way (re: decanting medicine)<br>It's very timesaving<br>An absolute disgrace (re: overpackaging) | 433<br>434<br>415 |
| | Unconcern with adhering to doses | Wouldn't have bothered me<br>None are things that are life threatening if I miss a day or take too many<br>Totally relaxed<br>There's no hassle or stress or anything, on it | 500<br>464<br>467<br>478 |
| Disturbance to Routine | Distracted by activity | Something distracted me and I was doing something unusual late last night,<br>I went to bed and forgot that I'd not taken my pills | 483<br>497 |

Table 11. Summarised Themes and Example Interview Quotes from Colin

| **Superordinate Theme** | **Theme** | **Quote** | **Line Reference** |
|---|---|---|---|
| Comparison to others | Chance affects health | I was pretty unlucky to have a clot<br>I'm just so lucky really | 469<br>729 |
| Knowledge | Medicine information | Medicine names, doses, timing | 26, 28, 29, 30, 31, 32 |
| | Seeking superior healthcare | That's when we decided to see the consultant privately<br>For longer than most people would recommend<br>Said 'stay on the clopidogrel for a further year'<br>Even though the reports say that its rubbish<br>He reckons that it's worthwhile<br>This consultant, who I trust, said take them<br>He's pretty well-regarded in his profession | 181<br>76, 77<br>97<br>218<br>219<br>390<br>653 |

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| | Seeking information | Read the leaflet about what they do and what the side effects are | 629 |
| | Self-Perception (Medical) | Always was fine and always is fine<br>Stable ever since<br>Been settled for quite a long time<br>Not in the last, probably nine years<br>Been taking them for such a long time<br>Drug has built up inside me | 147<br>161<br>202<br>505<br>338<br>340 |
| | Self-Perception (Fitness) | I managed a good peak time<br>A very good walking time | 64<br>153 |
| | Financial exchange to access healthcare | The National Health wouldn't provide them<br>BUPA don't think it's entirely necessary<br>Certainly our GP, they won't pay for that. That's up to me.<br>Surgery stopped paying for Omacor, it was do it yourself, if you want it<br>I can afford it, let's put it that way. | 83<br>137<br>138<br>141<br>452 |
| Considering the future | Continuous future | I just have to take these forever | 169 |
| Assimilation into lifestyle | Initial difficulty | It was all so new then<br>They just said you're on these, and go<br>Wasn't in the best for a couple of days<br>A bit difficult to know what each one was doing<br>Felt disappointed that I was going to take medication | 22<br>178<br>136<br>37<br>172 |
| | Taking medicine is unremarkable | Just as routine as having a cup of tea<br>Just take them and get on and do things<br>It takes 30 seconds, what's the problem? | 379<br>391<br>404 |
| | Unconcern with missed doses | I don't notice that I've taken anything | 209<br>366 |

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| | | I don’t get worried if I don’t take them | 497 |
| | | I don’t notice on a daily basis | |
| | | I miss one then never notice any difference | 501 |
| | Location of medicines | In a little pouch, there the whole time | 293,294 |
| | | Leave them out, just to remind me | 290 |
| | | Take upstairs, to be by my case | 607,608 |
| | | Take out the next morning’s medication | 610 |
| | | The evening medication, and put cling film over that | 612 |
| | | Will always have that in my pocket (re: GTN spray) | 973 |
| | | Whereas I’ll clear everything else out of my pocket | 978 |
| Disturbance to Routine | Distracted by activity | When all the family were here | 312 |
| | | The routine is a bit different (re: holiday) | 591 |
| | Change of timings | Timing dosages to that of the place we are going (re: time zone change) | 327 |
| | | Might be wider or less | 329 |

Table 12. Summary of Themes as Mentioned by Participant

| **Superordinate theme** | **Subtheme** | **Mentioned by Participant** | | | |
|---|---|---|---|---|---|
| | | Gaye | Beki | Chris | Colin |
| Comparison to others | Health conscious | • | • | | |
| | Unusual case | • | • | • | |
| | Parallel self | | | • | |
| | Compare to acquaintance | | | • | |
| | Compare to relatives | | | • | |
| | Chance affects health | | | | • |
| | Dislike of being labelled with diagnosis | | • | | |
| Knowledge | Medicines information | • | • | • | • |
| | Question cause | • | • | | |
| | Question medicines | • | • | | • |
| | Self- Perception (Medicines) | • | | • | |
| | Self- Perception (Fitness) | • | | | • |

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| | Self-perception (Medical) | | | • | • |
| | Cynical of care | | • | | |
| | Overcome medicine issue | • | | • | |
| | Seeking information | | • | | • |
| | Theoretical knowledge | | • | • | |
| | Practical knowledge | | | • | |
| | Follows professional advice | | • | | • |
| | Seeking superior healthcare | | | | • |
| | Paying for healthcare | | | | • |
| | Sharing knowledge | • | | | |
| | Strength in number | • | | | |
| Considering the future | Planning ahead | • | • | | |
| | Indefinite | | • | | |
| | Continuous future | | | | • |
| | Unknown future | • | • | | |
| Assimilation into lifestyle | Initial overwhelmed | • | | | • |
| | Concern for timing | | | | • |
| | Continue as usual | | | • | • |
| | Adapting to incorporate change | • | | • | |
| | Taking medicine is unremarkable | • | | • | • |
| | Unconcerned with adherence | | | • | • |
| | Child is priority | | • | | |
| | Concern for partner's anxiety | | • | | |
| | Made own system | | | • | |
| | Concern for efficiency | | | • | |
| | Constructed relationship with regular medicines | | | • | |
| | Physical issue | • | | | |
| | Side effect tolerated | | • | | |
| | Side effect unacceptable | | • | | |
| | Location of medicine | | • | • | • |
| Disturbance to Routine | Being out of the home | • | • | • | • |
| | Being on holiday | | | | • |
| | Distracted by activity | | • | • | • |
| | Changing of timings | | | | • |

## Discussion

This study has produced themes that add to our understanding of the experience of medicine taking following a myocardial infarction. The participants discussed medicine taking through four superordinate themes. Firstly, they *compared themselves* to others, often using this comparison to bolster their sense of wellbeing and provide optimism about themselves.

Secondly, *knowledge* was important to them, to help them construct an understanding of their condition and its management. Thirdly, the participants all considered the *future* in some form, thinking of it as either a constant or an unknown concept. Fourthly, participants discussed ways that they fitted their *medicines into their lifestyle* each making unique adaptations to manage their individual medicines. A related theme to lifestyle, all participants discussed how *a change to their routine* adversely affected their medicine taking. The study offers an interpretivist perspective in an area weighted towards quantitative research. The themes provide patients' perspectives on medication, extending beyond the simple representation of adherence as either intentional or unintentional, helping therefore to give context to people's engagement with medication following a myocardial infarction. These themes could help guide practitioners to provide more patient-centred care in future health consultations. They also show that patients adapt medicine taking into their lives in various and unique ways and a tailored approach to support them would be appropriate.

Currently medicine adherence support is provided to this patient group at the primary healthcare level through GP services, where the main aim is to integrate hospital discharge and return to independent home living through a programme of cardiac rehabilitation. While social support and cardiac rehabilitation have been well documented to improve treatment outcomes and quality of life measures, it is also apparent that recovery is a complicated and multifactorial phenomenon. An important positioning paper by the European Association of Cardiovascular Prevention and Rehabilitation highlights the complex role that psychosocial-related factors play in both the genesis and recovery of CHD (Pogosova et al., 2015). For example, psychosocial factors such as stress, anxiety and depression are implicated in the development of CHD, can be caused by CHD, and even reduced by CHD—the latter occurring when family rally round to increase social support following a diagnosis. The paper also discusses the complex ways that psychosocial factors influence cardiac outcomes and recovery, and how these factors can overlap and work in multiple directions, for example acting as barriers to lifestyle changes and treatment adherence. This complexity is in line with the themes untangled in this analysis, some of which conceptually overlap and affect one another, further emphasising the need for a patient-centred approach.

The theme of comparison to others and seeing one's own health protective behaviours as superior to others, could be construed as participants' way of evidencing their own health, maintaining control, and/or providing self-reassurance. This theme of comparison to others was also discussed in a narrative analysis of patients taking anticoagulant medicines to prevent stroke (Hawking et al., 2020). In that study, participants also constructed themselves as superior to others, evidencing their good intentions for example as good adherers while non-adherers were 'wasteful' or 'ungrateful'. Although a study of a different patient group, it agrees with this study that participants were keen to portray themselves as being healthy, adhering to medicines and positive lifestyle measures, and seeing others as having less favourable circumstances in terms of health. They found that missing doses was described as due to external circumstances of timing and location, and not linked to a personal trait. This supports the notion that participants are constructing an identity of positive health and higher morals than others to find comfort and gain control away from the tension of the uncertain. This finding highlights the need to consider the individual within group activities such as cardiac rehabilitation and social support groups, or when discussing benefits of treatment in terms of 'most patients'.

In the current study, the theme of knowledge is important because of its role in creating coherence whereby a clear model of treatment helps participants remove uncertainty and regain control of their self over their illness. Another study of the meaning of medication to patients also explored the role that knowledge and meaning play in helping patients understand and manage their medication (Shoemaker & Ramalho De Oliveira, 2008). That study found the medication experience to be a meaningful encounter, with positive or negative bodily effects, and an unremitting nature which could cause patients to question the need for it. The patients could even exert control over the medication through the expertise gained from taking it (e.g., take the medication only ‘when required’). Parallels can be drawn with the current study under the themes of both knowledge and assimilation into lifestyle, as participants described their own experience of medication effects and side effects, sometimes questioning the need to take medication, and importantly, gaining control over the medication by simply taking it and not feeling it was unwarranted. This emphasis on meaning-making could be thought of as a learning process and therefore prompt practitioners to think about where a patient is in their learning journey when delivering patient-centred care.

Similarly, the theme of thinking about the future could add to a sense of coherence and continuity. It is noteworthy that medicines adherence is not often framed in relation to the concept of the future. In pharmacy, the professional focus is traditionally upon medical history and the future extends only as far as the patient’s current valid prescription. The use of electronic transfer of record keeping, sharing, prescribing, and repeat batches of prescriptions, however, is potentially of benefit in terms of framing the future. This suggests more work could be done to investigate the impact of the current model of monthly prescriptions on patients’ sense of their future and in turn their medication adherence.

Medicine-taking exists within the constructed life-world of the patient, affects and is affected by it. The theme of fitting into lifestyle, drawn out in this study, highlights the interconnectedness of medicines and patients’ life-world. In this study patients had incorporated their medicines into their lives in unique and specific ways that were important to them and their beliefs. This adds further weight to the argument that reducing medicine-taking to ‘cause and effect’ is over-simplistic and of limited practical use. Against the good adherence work that the participants discussed, missing doses was attributed to being distracted, away from home, and timing issues. This is similar to the findings of a qualitative interview study of unintentional non-adherers taking medication for chronic conditions (Huyard et al., 2019), which found schedule change, life pressures, and location change to be reasons for adherence failure, suggesting that work to improve adherence should focus on these routine-related factors. The theme of ‘change to routine' is arguably not disease-specific but associated with medication taking in chronic illness more generally. Routine is rooted in physicality, related to time, space and occupation, which could all be manipulated through behaviour change therapies in order to remove practical and perceived barriers to taking medicines (Horne et al., 2019)(Horne et al., 2019). However, this type of intervention might only be relevant where patients are unintentional non-adherers, who aim to be good adherers (compared to others), rather than for intentional non-adherers who have no intention of taking medicines to start with.

A rich, detailed description of the lived experience of medication taking was achieved by the devotion of time, care and attention to the analysis. By using a case study approach, the results cannot claim to be exhaustive as there is no endpoint at data saturation as found in some qualitative methodologies. However, the use of comparison between cases has elicited superordinate themes for further investigation. In line with the ideographic nature of an IPA study, the results are not generalisable to larger populations but could be cautiously broadened to establish how they fit amongst different groups. IPA requires a homogeneity of sample with respect to the phenomena under investigation, and this was achieved through purposive selection of participants as all having experience of taking medication to prevent further AMI. This sample was similar due to their locality to the South-East of England, similar socio-economic profile and using UK NHS services to provide their healthcare. The results are not intended to be generalisable to other AMI populations outside of this specific context, but this is not the intention of IPA, instead finding universal patterns within specific detailed accounts drawn out by the analysis and thematic grouping work towards cautious claims of transferability (J. A. Smith, 2004).

An equal gender mix was observed, but results were not de-aggregated, contrary to SAGER guidelines (Heidari et al., 2016). The rationale for this was the small participant number and ideography of an IPA methodology, where the focus is individual voice, and summary of detailed themes resonating through those voices, as opposed to a broader aggregation of themes.

The self-selection bias of participants may have affected the result of this study, as perhaps volunteers tend towards individuals with positive or more extreme experiences. The situational pressure of an interview may have contributed to the participants feeling obliged to satisfy the researcher's line of questioning and present themselves in the best possible light, in the same way that a medical consultation might do (Anyan, 2013). The method of analysis, IPA, is a close first-person study, and so the participant is interpreted as being truthful and without agenda. Future study to examine the performance and politics of the talk during the same interviews could be completed using discourse or conversation analysis as a more critical method.

The use of IPA fitted well with the research question and compliments the model of patient-centred care where empathy and understanding are valued. This study contributes to the discussion of methodology in phenomenological studies as the integration of existential categories was found to be useful in the organisation and analysis of the data. Other studies have found an integrated phenomenological approach to be beneficial to the production of their findings, such as using similar lifeworld categories (Van Reenen et al., 2019), enactivism (Stilwell & Harman, 2021) and use of a revised grounded methodology (Køster & Fernandez, 2021).

This study has shown that whilst generalisations can be made, each patient's experience is unique and the meaning they associate to their behaviour and action is very personal. Therefore, the case study approach to developing medicine-taking interventions is a valid one. This is congruent with NICE recommendations for medicine adherence support to be patient-centred with interventions adapted to individuals (National Institute for Health and Clinical Excellence, 2009), and future work to be directed towards this area. This patient-centredness could be practised in pharmacy by way of motivational interviewing as an aid to medicine adherence, which in the UK is not currently a standard practice within the NHS.

Whilst fulfilling the aim of describing the medicine-taking experience, the relationship to medication adherence, and more importantly, *non*-adherence is unclear. All the patients discussed rarely missing their doses, and so perhaps future studies could solely include the elusive volunteer group of non-adherent patients. This echoes the findings of the Cochrane review of adherence interventions (Nieuwlaat et al., 2014), which concluded that more work ought to be completed with patients whose adherence is low.

## Conclusion

This study found the meaning of medicine-taking in this participant group was oriented towards reducing the unknown and reinforcing stability and cohesion in their lives. This finding, alongside the themes that the analysis generated could help practitioners assisting patients in their medicine-taking experience. The theme of *comparison to others* was found to confer a moral superiority to the self and offers comfort against uncertainty. The theme of *knowledge* and looking *towards the future* contributed to a participant’s sense of coherence, again reducing anxiety of the unknown. *Assimilation into lifestyle* could be considered a modifiable learned behaviour, and *medication routines* could be strengthened by activity, location and timing interventions.

Meaning making was unique to individuals and so adherence interventions should be tailored to personal experiences in order to be more empathetic and therefore more impactful for an individual patient.

The methodology highlighted the importance of considering the phenomena of adherence as part of the whole life of an individual, as it is the entirety of a patient’s world that imparts meaning to adherence. The ideographic approach of this study produced a rich dataset and aligns with a tailored intervention to improving adherence and with a patient-centred approach.

# Chapter 5: Constructed Grounded Theory

## Introduction

Following the IPA analysis, a detailed study of the participant's experience from a first-person perspective has provided details of overarching themes that participants considered the future, compared themselves to others, discussed building and maintaining a medication routine, and that knowledge was important to them. From the systematic literature review, the coverage and depth of previous qualitative studies has been detailed and confirmed that there is a lack of study in this area, and specifically no research of this kind nor multiple approaches have been undertaken.

This grounded theory study will propose a process by which the experience of taking medication to prevent a further AMI can be modelled.

## Reflexivity

After my introduction to participant recruitment organisation in the IPA study previously, the recruitment process momentum continued with the cardiovascular support groups. The iterative element involved trying to recruit equal numbers of men and women to the study, and then within interviews, coverage of particular areas of interest. After eight participants had been interviewed and analysed there were two slow periods of recruitment, and it was frustrating to continue trying to make contacts without result, it felt like there was a long gap, each time worrying that the study wouldn't complete fully, but also knowing that data saturation hadn't occurred.

The theoretical process was enjoyable to design, and went through several iterations including the idea that participants considered themselves to be lucky or healthy and afforded a level of protection as a result, the concept that surgery had fixed the participants, and they were waiting for something to get blocked again, with a plumbing analogy, and also that participants were in a period of limbo between their next big cardiac event, waiting with a type of final warning, such as having been given a yellow card in football. The end theory chosen that fitted all the participant's constructs, in that they had reached a period of stability by continually taking their medication yet still, control was external, such as how this affected their bodies with issues such as the experience of side effects and they depended upon their prescriber to fix the issue. After choosing nautical analogies, in part as a result of their frequent use by participants, such as 'nobody wants to rock the boat', and my realisation that my participants had a tendency to present themselves as being from the socioeconomic group that I would describe as 'the yachting classes' (they appeared to be middle class, white, often retired professionals who were physically and financially mobile, several discussed sailing as a pastime, and many talked about going on regular cruises as holidays). The perfect idioms took a lot of considered thought to fit the shapes and actions taking place in these concepts, but were exact in their match of the meaning attached. They were almost too good, making it look like the result had been forced into fitting a dapper phrase, and not the other way round.

In this part of the research, I encountered several participants who gave responses that I was not prepared for, such as participating in clinical trials and directing their GP to stop all their medications. At the time, I was concerned that the responses wouldn't fit into any model, and that adding the new concepts had 'ruined' all my previous ideas. As I considered them more, I found ways that made sense and still incorporated these outliers; in these cases, the crisis point which caused them to seek external assistance, and so the resulting process model is strengthened and made more robust because of including them. This fits with the constructed grounded theory procedure moving from an inductive process, iteratively back and forth and then towards a more abductive stage, as stated by Charmaz (Morse et al., 2009) (p137-138), "Grounded theory begins with inductive analyses of data and then moves beyond induction to create an imaginative interpretation of studied life. We adopt abductive logic when we engage with imaginative thinking about intriguing findings and then return to the field to check our conjectures."

There were several participants who I felt had lively personalities, requiring me to delicately balance their desire to talk, and my need to keep to schedule and manage the interview without them taking over the topics to fit their own agenda. One participant was very anti-medication, but I managed to fit his ideas into the construct by broadening the bodily effect concept to include the incongruence with internal belief, and labelling this as reaching a crisis point, rather than simply a bodily external effect. Looking back at the transcripts, the talk didn't go off-tangent, instead containing greater volume of words in general, and longer interview in general. The length of interview wasn't an indicator of the content, perhaps more a reflection of style and speed of speech.

The saturation point was filling up ideas around the presentation of side effects, and no further concepts were added following this after thirteen interviews, but I was very cautious, and included just one more participant, twice, to make absolutely certain.

# Paper C: Reaching ‘plain sailing’: A grounded theory study of the experience of taking medication to prevent a further heart attack

Abstract

Introduction

Following an acute myocardial infarction (AMI), patients are prescribed a daily regime of five medications to prevent secondary cardiovascular events. However, medication adherence in this patient group has been measured to be low, causing increased mortality, morbidity and healthcare system costs. Current interventions lack a formal evidence base, and so studying this experience could provide evidence to support future intervention work. This study used grounded theory methodology to create a process model of the experience of medication-taking in patients for secondary prevention of AMI.

Methods

Semi-structured interviews were conducted with fifteen people who took medication following a previous AMI episode. The interviews were audio-recorded, and transcriptions analysed according to constructed grounded theory.

Results

On returning home from hospital, participants built a medication-taking routine into their lives, 'Anchors away’. They balanced medication pros and cons, and were driven to remain stable, ‘Nobody wants to rock the boat’. Participants reached a crisis point, requiring their medication to be changed, ‘Man overboard!’. They presented this evidence to their prescriber, who made the decision about medication change. Medication-taking was driven by an overall desire to continue living, reaching ‘Plain sailing’.

Conclusion

Participants set up a new medication routine which required little effort to maintain. Side effects led to a crisis where they required their prescriber to make a medication change.

The non-prescribing medical team can improve their perceived role in patient care. The influence on adherence behaviours of the high social status conferred upon prescribers by patients is a point for further study.

Keywords

Acute myocardial infarction, Grounded theory, Medication adherence, Qualitative

## Introduction

Cardiovascular disease (CVD) remains the leading cause of mortality and morbidity in Europe, and in the UK, death from CVD is superseded only by cancer (Timmis et al., 2022). Acute myocardial infarction (AMI) is a severe and profound event associated with CVD, most often caused by the shift of an atherosclerotic plaque or an erosion of cell endothelium, leading to clot formation, ischaemia and cell death. Recent improvements in AMI prevention and treatment, through evidence-based pharmacological therapy and lifestyle interventions have led to a reduction in AMI mortality, yet the percentage of patients that die within 30 days of hospital admission has been measured to be 7.6% for the UK, and for survivors of AMI is associated with a significant impact to the lives of individual patients and their families (Townsend et al., 2016). In the UK, following an AMI, patients are discharged from hospital with a regime of five evidence-based cardioprotective medications to take. These secondary prevention medications are recommended by the National Health Service (NHS) in the UK as standard therapy in order to prevent recurrence of AMI, cardiac complications and rehospitalisation (National Institute for Health and Care Excellence, 2017). High levels of adherence to each medication, and also to all medications, leads to improved cardiovascular event-free survival (Choudhry et al., 2014);

adherence to medication is protective, leading to lower morbidity, and is associated with reduced hospital visits and healthcare costs (Plakht et al., 2020).

Medication adherence in the general population is sub-optimal, and similarly found in this patient group, having been measured to be as low as 66% (Naderi et al., 2012). The issue of poor medication adherence has been highlighted by the World Health Organisation as an important focus for addressing, with an often-quoted observation that improving patient adherence could be as important as new technological advancements (Sabaté E., 2003).

Attempts have been made to tackle poor adherence; in a meta-analysis of all medication groups, interventions have made a small contribution to improving adherence, yet none are universal nor significant (Nieuwlaat et al., 2014), (Wilhelmsen & Eriksson, 2019). To explain, in the AMI patient group, interventions such as telephone text reminders (Pandey & Choudhry, 2014), patient information leaflet mail-outs (Ivers et al., 2020) and direct pharmacist counselling have been used (Jiangbo et al., 2021), finding respectively a 20% improvement in adherence, no effect on adherence and a reduction in AMI recurrence rate of 7.14% versus 18.57% in the control group.

Medication adherence is a complex multi-faceted behaviour which is not fully understood. Yet, there are many proposed theories and behaviour change interventions designed to improve adherence (Easthall & Barnett, 2017). The NHS guideline to support medication adherence for patients suggests working with individuals through a patient-centred approach (Nunes, V, Neilson, J, O'Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009). In order to better understand the patient perspective of medication adherence, a qualitative study could form the basis of future theoretical models and interventions (Braun & Clarke, 2019). Qualitative study is currently underused in cardiovascular research and, echoing the communication break described by Braun and Clarke, patient experiences can be overlooked by both medical practitioners and researchers, and patient beliefs, values, and motivational factors are presumed or omitted by quantitative cardiovascular study paradigms (McIlvennan et al., 2019).

The aim of this study was to propose a theory of the process by which patients adjust and maintain a cardioprotective medication-taking routine into their lives, and the actions and relationships involved in this process. Using patient interview data, constructivist grounded theory (Charmaz, 2006) was used as an inductive, iterative approach to building a proposed process as a result of analysis of the data. Grounded theory (GT) is a method of constructing a process theory, which simultaneously addresses issues of methodological individualism by use of a rigorous methodology while also using the skilled position of the researcher to allow an informed interpretation of the data, the meaning behind actions taking place and subsequent resulting process model (Charmaz, 2016). GT has been used numerous times by the current research group in order to study medication practices, creating categories and new all-encompassing insights within each area, to provide tangible lived world factors to build upon for further work (Almutairi et al., 2018),(Ibrahim et al., 2016),(AlOmeir et al., 2022). To give a detailed breakdown of the categories in the process, a paradigm model framework is created to illustrate the coverage of themes within each category, as detailed below (Strauss & Corbin, 1998).

## Methods

### Design

This study used a constructivist GT approach to propose a theory of the process of taking medication to prevent a further myocardial infarction by a patient, describing their actions and causes, and factors that affect a patient’s ability to adhere to their medication regimes. GT uses a constant comparison methodology to elicit a process theory grounded in the words and experiences described by participants including multiple viewpoints, perspectives and individual realities and provide a detailed explanation of the experience for most participants (Charmaz, 2006). The study reporting and design was guided by the Consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007).

## Recruitment and Data Collection

Ethical approval was obtained from the University (UREC 18/36). Fifteen participants were recruited from a promotional poster sent by email to targeted cardiovascular support groups within central and southern England, and cascaded by department lists within the University. The criteria for inclusion were adult individuals with a diagnosis of AMI, who had been prescribed medication for secondary prevention.

Prospective participants made initial contact with the first author and through email, the study information pack was sent in response, and signed consent returned by participants who wished to continue into the study. All participants were offered a choice of in-person, online or telephone interview at a prearranged time. They were pseudonymised prior to interview.

All interviews were conducted by HP in a private office, and audio recorded. Fifteen interviews took place between June 2019 and March 2023. Interviews ranged in duration between 17 mins for a pilot interview which was included in the data, and 69 mins, with an average time of 47 mins.

A semi-structured interview schedule was devised to guide the interview questioning, based upon literature for development of an interview protocol (Kallio et al., 2016). In line with grounded theory interviewing, this schedule opened the participant narrative, following a couple of easy response-as-list questions, with a broad question, ‘Could you describe your experience of starting medication...’ (Simmons, 2010). Field notes were taken during the interview as a memory aid and prompt for probing questioning, and longer notes were written up at the end of each interview to describe what happened, thoughts and future refinements or lines of enquiry, which would later be used in the writing of theoretical memos to guide the analysis. The interview was concluded when all questions had been sufficiently answered, all probes and lines of further enquiry had reached an end. Each interview closed by asking the participant if they would like to add any more and asked for a suggestion of a question that could be used in the future. The debriefing of each participant then took place with thanking the participant and explanation of what would happen next. Participants were not offered any monetary incentive for participation, but their value as participants was stated in the study information pack, and care taken to ensure they received reciprocal respect and professional behaviour throughout their interaction with the researcher (Winter et al., 2022).

Each interview was audio-recorded as an MP3 file, then transcribed verbatim to text using Word software; the transcripts were checked alongside audio playback to confirm accuracy. The transcripts were broken down into lines according to the flow of dialogue, following the rhythm of conversation, most often phrases or sentences containing chunks of distinct and coherent meaning. The transcripts were uploaded into NVivo 12 Software for organisation and display of the analysed data. A copy of each transcript was also returned to each participant, in line with member checking and transparency, to enable participant comment or redaction if requested. No participants wished to amend their transcripts.

## Data Analysis

Data was analysed concurrently with collection, which prompted lines of further investigation in line with the iterative process of GT method (Charmaz, 2006). Data lines were assigned a descriptive code according to the meaning contained in each line. Following this stage, only lines that related to medication-taking were selected for further rounds of coding. The data lines were open coded, where constant comparison analysis was applied to the lines of text placing each into that of an existing code, or a new code was defined. Categories were then created by clustering similar codes together, and differences were conceptualised (Morse et al., 2009). Theoretical memos were written to further conceptualise the properties, theoretical ideas and constructs. The theoretical memos were used to guide the interpretation and open discussion about meaning during the analysis, also allowing for a deep interrogation of the texts.

Axial coding was undertaken, which connected between the categories, and a coding paradigm was created, defining the conditions, context, actions/interaction and consequences, which constructed the coded categories into an interconnected framework model of the phenomena (Strauss & Corbin, 1998). Selective coding was then used to further elicit the core category around which all the categories are integrated.

All coding was done by HP, a PhD student and community pharmacist. During the analysis, coding was shared and discussed with PD, a senior academic in pharmacy with specialisms in psychology of pharmacy. Through a process of continual critical reflection, data were organised into paradigms and the relationship of categories within the paradigms was proposed and refined by both authors working together. These reflective stages took place during data collection, allowing for theoretical sampling where focused questions and lines of enquiry were added to the interview schedule. Theoretical saturation was achieved when no further codes were added to the categories created, and all gaps in the emerging conceptual scheme were filled. Saturation was considered achieved after interviewing and analysis of data from thirteen participants, then the data from two further participants verified saturation.

The ethical approval and consent gained precludes the full transcripts from being made available publicly, but the full coded data categories can be found in supporting information.

## Results

This final model encompasses three key categories of experience; an initial stage of adaptation and routine-building prompted by participants arriving home and needing to incorporate new medication into their lived world: '*Anchors away*'. The second category was a stage of navigation resulting from participants continually balancing the pros and cons of taking their medicines, needing to maintain stability. There was a strong requirement to continue with the prescribed treatment as '*Nobody wants to rock the boat*'. The third category occurred when stability was upset by an event that required medication changes, '*Man overboard!*'; participants brought a case to their prescriber, who then made medication change decisions, and then participants adjusted and continued their routine medication-taking. The core category that informed all medication-taking actions relating to these categories was the desire to continue living, reaching ‘*Plain sailing’*.

Figure 6 shows the process model of the results of this GT analysis.

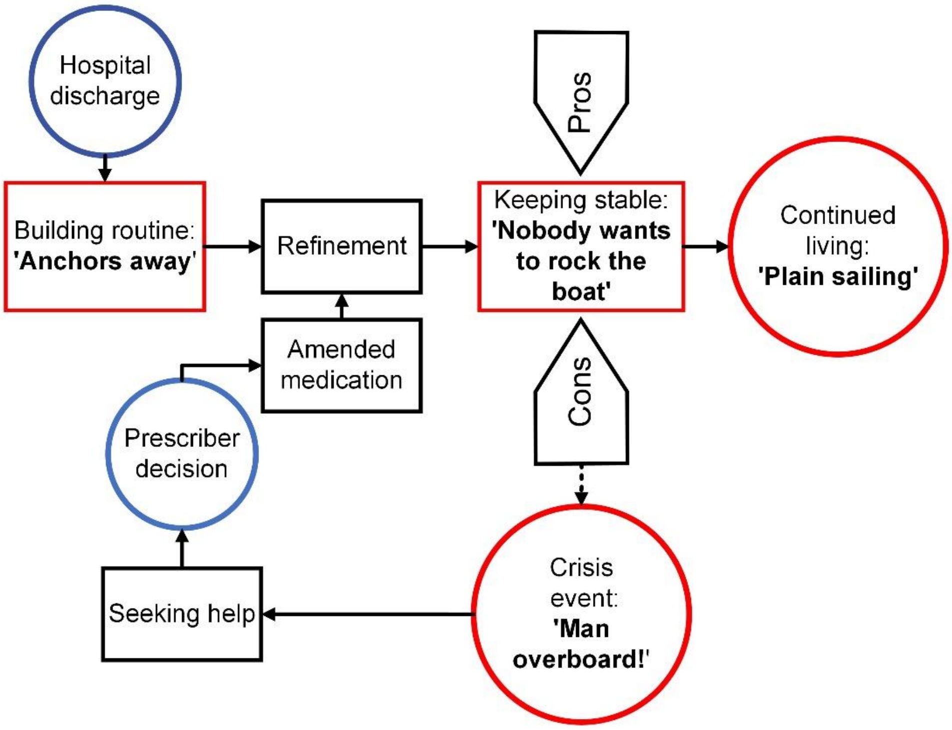


Figure 6. The grounded theory process model of the experience of taking medication to prevent a secondary acute myocardial infarction. The core category of Continued living is produced as a result of (1) Building a routine ‘Anchors away’ and (2) Keeping stable ‘

<u>Category 1: Building a routine – ‘Anchors away’</u>

This initial category involves the building of a routine, as described in table 13.

Table 13. The paradigm model for category 1: Building a routine – ‘Anchors away’

| **Context: Building a routine – ‘Anchors away’**<br>Participants treated in hospital following AMI, in the UK guided by NICE, are usually discharged home with several medications according to standardised procedures and asked to take them as instructed. *How do they build medication routine into their life?* | | |
|---|---|---|
| **Causal conditions** | **Actions/interactions** | **Consequences** |
| Becoming responsible for taking own medication<br>Becoming responsible for keeping medication out of reach of others<br>Becoming responsible for keeping medication with them<br>Being observed by family<br>Awareness of medication physical characteristics<br>Feeling emotion – stress, anxiety, fear, loneliness, uncertainty<br>Recognition of lack of knowledge of medication and disease<br>Self-care<br>Enthusiasm and trust<br>Support from family and medical team<br>Medical team imply expectation that medication is taken and provides benefit, reiterated at cardiac support group, consensus opinion<br>Medical team have high status, professional expertise and | Placing medication in the right room (e.g. kitchen to allow it to be taken with water, bathroom as routine prompt)<br>Placing medication in safe location (e.g. cupboard, worksurface)<br>Keeping medication in the same location<br>Taking medication along when away from home (e.g. in the car, packing for holiday )<br>Reading cues on packaging to guide adherence (e.g., sun and moon)<br>Using existing routines to incorporate medication routine (e.g., breakfast and bedtime)<br>Transferring medicines into another convenient container (e.g., Tupperware, pill bottle, compliance aid)<br>Preparing a memory cue (e.g. visual reminder, phone alarm)<br>Using previous experience of taking other medication or learning from copying others<br>Checking back visually that the previous dose has been taken<br>Pattern recognition; synchronising dosages and knowledge of the correct visual or sequence of medication<br>Habit-forming | Taking medication as instructed<br>Awareness when a dose has been missed<br>Automatic activity requiring little effort<br>Experiencing bodily effects<br>Not noticing any effect<br>Having knowledge of medication side effects, mechanism of action, treatments<br>Not wanting to take medication; an unknown entity, chemical, stigma, reminder of illness |

| | | |
|---|---|---|
| knowledge, and have gifted this to the patient during their hospital stay | Actively seeking knowledge, researching AMI and treatments<br>Reading passive information (e.g., medication patient information leaflets, BHF leaflets, books, newspaper articles)<br>Unspoken social consensus that taking medication is a desirable activity<br>Patient feels indebted to medical team | |

### Causal conditions

Following hospital discharge on a ‘raft of medication’, participants returned home, and a period of adjustment took place. Participants described they experienced negative emotions; fear, anxiety, loneliness and uncertainty as shown in table 1.

### Actions/ interactions

To overcome this, participants were driven to seek information about their diagnosis, in a period of learning, seeking out sources to complete gaps where they recognise that they lack knowledge.

> “I came out of hospital feeling abandoned and lost and not knowing what to do next. When I got home, I was sent home, with nothing just these tablets and 'take them'… (Ola T)”

Participants described taking on the new medications with a sense of responsibility to take them and keeping them safely and accessible at appropriate times. There was a strong desire to comply with hospital directions, with deference to both the authority and knowledge held by the prescriber, and also with a debt of gratitude for the work and care that they received.

"So I am. I am fairly well organised, I don't. I don't play about with it. I do what I'm told. (Tony T)"

Consequences

The location of medication is important in establishing a routine, having it in the room at the right time, and in the same place. Also, participants made plans or learnt from previous experience, for example when taking their medication when outside of the home, being out for the day, away on holiday or when distracted by unusual activities.

The act of taking medication was discussed as being built into a routine for participants, featuring memory cues such as timing aids, adding it to an existing routine, reading packaging cues, actions towards convenience and ease such as changing the container, checking back visually and activity repetition for reinforcement into habit.

"It's second nature. Don't really think anything of it. It's just part of my daily routine now. (Ron P)"

This initial introductory stage works towards creating a habit so that medication-taking becomes interwoven into their lives; participants take their medication as directed, they notice when they've missed doses, learn from instances when they've missed, and prepare methods to avoid this repeating, and refining their process.

Category 2: Keeping stable – 'Nobody wants to rock the boat'

Once patients had built a routine, the following stage involved the urge to stay stable, and navigate around problems, as described in Table 14.

Table 14. The paradigm model for category 2: Keeping stable – ‘Nobody wants to rock the boat’

**Context: Keeping stable – ‘Nobody wants to rock the boat’**

*Pros: Participants have incorporated medication routines into their lives, continuing to take it to prevent a future cardiac event. What keeps them going?*

| Causal conditions | Actions/interactions | Consequences |
|---|---|---|
| Knowledge that treatment is life-long<br>Knowledge that treatment follows a standard regime, universal<br>Desire to continue current state of health, return to previous health, normal function, have target future goal | Keen to continue taking medication<br>Seeing further information about treating their condition through books, leaflets, internet, newspapers<br>Attending medical reviews, signed off by hospital consultant, switch to GP care<br>Participating in clinical trial<br>Adopting a stringent diet regime | Compliant medication-taking<br>Identifying as a patient, being one of ‘you lot’.<br>Being seen as the person that did something different, a talking point<br>Further understanding alongside practical knowledge, symptom and side effect awareness<br>Individual patients continue to take medication in line with group expectations ‘nobody wants to rock the boat’<br>Medical team instructions are followed |
| Being offered a place on NHS local cardiac rehab programme<br>Desire for social connection with similar patients | Attending cardiac rehab, finding it beneficial, going through the motions, a programme<br>Attending cardiac support group, committee role<br>Becoming a patient advocate, educator | Gaining physical confidence, socialising<br>Support outside of family and medical team<br>Fixed period of rehab attendance<br>Building longer-term relationships<br>Reinforcement of group conformity to adherence, not questioning<br>Sharing experiences, knowledge, comparison |
| Patient remains stable, no bodily change<br>Not noticing any effects from medication | Evidencing continued stability - Creating knowledge with medics of biometric measures: BP, cholesterol, fitness levels | Contentment and continuation with treatment |

**+Simultaneous Context: Confounding factors**

*Cons: At the same time, participants have doubts, actions that disrupt their routine, the consequences are a barrier to medication taking. A change to routine will result in missed dosages for a short period, and severe bodily effect will result in stopping medication taking entirely. Overall, despite the presence of these factors, participants continue to take medication.*

| Causal conditions | Actions/interactions | Consequences |
|---|---|---|
| Patient's reluctance to take medication; wish to stop medication, reduce dose, reduce frequency<br>Limited or incongruent information<br>Feeling impersonal by medical team issuing of standard universal treatment<br>Information noise; gossip, broadsheet and tabloid newspapers, 'statins, the dirty word'<br>Seeking alternative options<br>Preference for more natural treatment, dietary<br>Experience of bodily effect | Reluctance to continue taking medication<br>Favouring diet and eliminating medication<br>Feeling medication hasn't been appropriately tailored to suit their bodies<br>Misunderstanding, 'I don't have high cholesterol/ BP'<br>Questioning the cause of noticeable bodily change, challenge and collecting evidence | Begrudging medication-taking<br>Comparison to others, 'the man in the village who stopped all his medication'<br>Patient recognising gap in their knowledge - seeking specific side effect information, experiential testing, deduction of cause<br>Evidence concludes bodily effect to be a side effect of medication<br>Patient requiring collaboration with medical team, need to stop medication, need to amend medication dose, drug. |
| An NHS rehabilitation programme is offered to everyone | Avoiding cardiac rehab; seeing it as patronising, beneath them, COVID cancellations | Reinforcing ideas of being different to 'normal' heart attack patients |
| Noticing bodily effects (e.g., gradual muscle pains, cough, sudden blood loss, violent diarrhoea) | Concluding bodily effects are due to medication, 'side effects'<br>Attributing bodily effects to coincidence<br>Hospital admission for urgent treatment of medication side effect | Questioning medication or rationale, building a case to present to medic<br>Presenting case to medic for discussion and decision: dismiss, dose amendment, medication change, stop<br>Traumatic event |

| | | |
|---|---|---|
| Being outside home (e.g., local activities, on holiday, travelling)<br>Disruption to routines (e.g., a night out, guests in the home, distractions)<br>Memory, attention, missed cues | Missing dose<br>Taking dose later than usual<br>Taking dose as soon as remembered | Not worried, happens infrequently, drug quantity built up by regular taking |

### Causal conditions

At this stage, participants were continually balancing the pros and cons as they arose, and continued to take medication. They were driven by a desire to return their lives to a perceived ‘normal’ state, a stable stage.

> “I, I offset that against the benefits that the drug is supposed – there's this sort. Of compromise in my mind eventually which. I hope will one day be proved. (Rod F)”

### Actions/ interactions

Remaining stable was indicated by not noticing any effect of taking their medication, receiving biometric test results that were within ‘normal’ range, and noticing that their activity ability level improves. Bodily stability was also indicated by change in care from cardiac consultant care in hospital to GP care in their local surgery, which could also involve a cardiac nurse or pharmacist monitoring.

> “Whatever, you do a couple of tests and they say ‘no, you seem stable’. And I say ‘great’. Haha. I seem to be on this plateau, uh. Unless something else appears. A new symptom. (Phil H)”

Participants were emotionally strengthened by having family to support them, and the knowledge that treatment was lifelong and standardised for all patients. Similarly, they implied there was a system expectation from healthcare professionals that treatment is adhered to, which is reiterated during attendance at cardiac rehabilitation and from cardiac support groups, and amongst patients a group culture of quiet compliance with medication-taking, ‘nobody wants to rock the boat.’

At this stage, participants had time to find more in-depth information about their illness and how to contribute to their own health. They decided upon their own lifestyle actions, such as making diet adjustments and exercise routines. Participants also sought alternative treatments, such as participating in clinical trials or extreme dietary regimes.

Participants had a large amount of generalised knowledge about their medication, side effects, treatment and disease, and also specific information about their personal biological measurements. They saw themselves as belonging to the group of ‘patients’, but this had differing meanings to people, and also within different contexts for individuals. Most participants were keen to make a personal contribution to their continuing health through their own actions, including responsibility for medication-taking but also making efforts towards keeping ‘healthy’.

> “Let's just keep taking the drugs and living the life I'm leading now. (Tony T)”

Being able to share and compare their experiences was a beneficial social aspect of attending cardiac rehabilitation and support groups. Some participants considered these groups patronising and saw themselves as unsuited or outsiders of the group membership. Some participants were unable to attend in person, due to social distancing through COVID-19.

Simultaneously, participants are balancing the perceived benefits with disadvantages and deciding to continue with treatment. There was an underlying resistance to both having to take medication, and the concern around medication itself, with a preference for not having to take them.

“I would, I would – love – not to have to take them, and I’ve asked my GP – endless times, um – and he’s just said no. You have to keep on taking them. (Gaye A)”

Their treatment knowledge caused incongruence with their understanding of their body, such as being given medication for reducing cholesterol when they knew they didn’t have high cholesterol. The statin group of medication was considered the most troublesome by most patients from their personal experience of side effects and also culturally, from hearing the stories of other’s experiences.

“Uh, yes, because. When I've queried the tablets, they keep saying I'm on the right. Cocktail of tablets so. Well, one of them, one of them's for, the stomach. Or what's the stomach got to do with the heart? (Lea S)”

Some patients considered the standardised treatment regime to be insensitive to their body’s requirements, and often noticed information from newspaper reports and popular science ‘MD bestseller’ books which often challenged the cultural convention that medication is beneficial to health. Again, patients often mentioned statins prominently, as the medication ‘they reckon everyone should be taking', but also ‘statins, the dirty word’.

Consequences

Here, medication-taking required little effort following the establishment of routine, ‘just get on with it'. Participants recognised changes in the body, and attributed them to side effects, which were noticed but not problematic.

### Category 3: Crisis leading to medication change – ‘Man overboard!’

The final category that affected participant’s progress towards continued living happened when the negative aspects of taking medication overwhelmed them, leading them to reach a crisis point about medication, in which they presented a case for changing their medication to the prescriber who then made the decision to amend medication, as shown in table 15.

Table 15. A paradigm model for the category 3: Crisis leading to medication change – ‘Man overboard!’

<table>
<tr><th colspan="3"><b>Context: Crisis leading to medication change – ‘Man overboard!’</b><br>Participants reach a crisis point in their medication-taking where they perceive negative factors to outweigh the positives, and decide that their medication requires changing – how does this happen?</th></tr>
<tr><th>Causal conditions</th><th>Actions/interactions</th><th>Consequences</th></tr>
<tr><td>Patient experiences bodily effect, seeks information or uses prior knowledge to confirm this as a side effect of medication<br>Patient regular medical review, prior booked appointment<br>Patients present a case of evidence to the medical team linking their knowledge and bodily experience or biometric data to their medical team<br>Patient presents the medical team with issue requiring urgent medical attention (e.g. acute symptoms, BP measurements)<br>Patient perceived time constraints and workload pressure for medic</td><td>Medic amends medication without discussion due to biometric result or change of medication protocol<br>Patient has opportunity to talk with consultant or GP, a dialogue takes place enabling patient to discuss their issue and ask for a change or advice.<br>Dismissal by GP due to unwarranted symptom, reluctance to change superior prescribers' treatment; ‘singing from the consultant’s hymn sheet’<br>Patient not in a position to have a conversation, power imbalance, lack of evidence<br>Seeks support from pharmacist or cardiac nurse, sharing their experience and requires further information</td><td>Patient successful in bringing about desired change outcome through medical consultation<br>Consultant action to change of medication: drug initiation, increase or reduction of dosage, swap within group of medication, stops medication<br>GP action to amend dose, swap within group of medication, reduces dose, stops medication<br>Patient unsuccessful in bringing medication change, continuation as before; patient frustration, lack of empowerment</td></tr>
</table>

Causal conditions

Bodily effects were experienced by the participant, which they attributed to medication side effects. These effects could be acute, requiring immediate medical attention, but most were described as happening gradually and unrelated to the length of time they had been taking the medication.

“This was an absolute nightmare 'cause it caused my veins to swell look like something in a horror film. And so my GP took me off it. (Carl L)”

Action /interactions

Participants collected evidence that medication was the cause and sought further information to confirm their suspicions to themselves. Some participants sought advice from their pharmacist or cardiac nurse as to how to proceed. They presented their evidence to their prescriber to request a change in their treatment. Medication change happened to most participants at some stage; only one participant didn’t mention experiencing any change from their initial treatment. One participant used their biometric results alone to present to their prescriber as evidence for change, without the presentation of any side effects. Of importance is the finding that no participants discussed amending taking their medication without consulting their prescriber.

“Uh, especially with the statins I was getting a lot of aches in the lower limbs. And I raised that with people at Capital and they said, you know. (Phil H)”

“...Listen to, listen to my complaints and after a while. Uhm, thought I ought to go on, on the losartan instead. (Mark K)”

Consequences

Prescribers changed medication within the drug class, dose reduction, or stopped. Medication was also changed directly by the prescriber because of biometric test results such as blood pressure readings. Sometimes the side effect evidence was disregarded by medics, resulting in no change taking place, and the participant being frustrated and feeling of being ignored.

Some participants didn't attribute their symptoms to medication, suggesting the cause was idiopathic or coincidental.

Medication changes were then adopted into participant's established routines as before, with direction towards continued living.

### Core Category: Continued living – reaching 'Plain sailing'

The core category by which medication-taking took place was the need by patients to continue living their lives captured by the idiom 'plain sailing', describing that the process had become easy and smooth, as set out in Table 16.

Table 16. A paradigm model of the core category: Continued living – reaching 'Plain sailing'

| **Core Category: Continued living – reaching 'Plain sailing'**<br>*Participants are building a medication routine, 'Anchors away', keeping stable, 'Nobody wants to rock the boat', and passed through crisis points 'Man overboard!'. What is the underlying reason?* | | |
|---|---|---|
| **Causal conditions** | **Actions/interactions** | **Consequences** |
| Taking medication produces continued cardiac stability<br>Medication as shield<br>Medication as insurance<br>Medication builds up a bank with duration of taking<br>Experiencing no change in bodily effect | Patient requires no medical intervention<br>Patient moves from hospital care to GP care – from hospital consultant to GP surgery/ nurse specialist<br>Patient has less frequent medical reviews | Medication prolongs life<br>Medication prevents another cardiac event |

Participants described taking medication as a means to maintain this health stability, and survival therefore prolong their lives. They also frequently mentioned the desire to return to 'normal'. They considered medication as a protection, a barrier or insurance against the uncertainty of the future.

“Oh my medication has to be top of the list. It's keeping me alive. (Ola T)”

“I’m here. (Chuckle) And I’m pleased that I'm here, so if it helps me to continue being here, then it’s worthwhile. (Gaye A)”

Participants saw medication-taking as providing a long-term cumulative effect and were less concerned about single missed doses. All participants claimed to not miss doses frequently. Interestingly, many of the participants discussed having a second AMI or further cardiac complications but didn’t relate this to their medication-taking.

## Discussion

This is the first study to the best of our knowledge that proposes a theoretical process of medication taking in patients following an AMI. It informs our understanding of the broader picture and context of this experience, providing categories for starting points and the specific details elicited here are of practical use when working to assist patients. This study found that the core concept for medication-taking by these participants was the desire to continue living. The stages of this process involved the establishment of a routine, balancing positive and negative perceptions but maintaining stability, until an event happens and negative medication factors become overwhelming, prompting the participant to ask for medication change from the prescriber.

The first stage is instigated by returning home following hospital discharge, and involves the need to amend their lived world to accommodate a new medication regime. This stage encompassed the establishment of routine and habit, and was accompanied by information-finding to better understand and experiential learning of the medication-taking process.

The second stage continued this practice, it happened without effort and produced no noticeable effect to the patient. The participants performed this activity automatically, apart from when away from home such as on holiday, or their routine was disturbed. This is the desired paradigm stage for a participant to enter into, leading towards continuity of process, effortless medication-taking, and evidenced by bodily and perceptual stability. In this stage, participants moved towards their goal of continued living, evidenced by bodily stability and moving to generalised medical care, from hospital cardiologist to GP review.

The third paradigm could occur at any time, as a result of either bodily effects taking place or participant questioning, reaching a crisis for which they required external help. This caused the participant to seek further knowledge, mostly in the form of medical information, but could also come from other people's experiences. Bodily effects were mostly perceived to be due to medication and described as 'side effects'. Participants sought evidence to affirm their suspicions, backed up with their personal experience and experiment to prove a causal effect. They asked a nurse or pharmacist to check or went directly to the prescriber to present this evidence to them, opening a discussion to seek medication change. The practitioner either changed the medication group, reduced the dose, or made no change. Following change, the cycle then reset, and the process continued as before.

This process model is built upon constructionist principles and interrelation of themed actions, but each individual's experience differed and the meaning of medication and how they organised this into their lived experience was very personal. This model aligns with the concept analysis that medication-taking is an interplay of ambivalence by the patient, and a pragmatic, ongoing process (Hillman et al., 2020). Our findings agree that medication-taking is contextual and nuanced for participants. In general, their position was that of dislike of taking medication, but with an understanding of the need to take it and learning to adapt their routine so that the action required little effort and produced no noticeable effect, describing their stable stage as to 'just get on with it'. There was an underlying system-implied imperative to take medication, reinforced by fear of repetition of AMI and that medication offered protection against this and a means of continued living, but also there was a strong respect of, and deference to the status and knowledge of their prescriber.

GT has been used to previously study AMI patients' lifestyle changes. A study from 1978 found this a three-stage process of immobilisation, figuring what should, should not and what to cut back, and adjusting to the new normal of their situation (Mullen, 1978). Similar GT studies have built upon that work to describe early lifestyle stages following hospital discharge and recovery from AMI as regaining control, coming to terms, learning to live and living again (Johnson & Morse, 1990). The study included changes in bodily ability and smoking and alcohol habits, in perhaps a cultural perspective that differs from our current view, and a reminder of historical context in any study. A study of women's ability and lifestyle changes over a longer period found women's roles required identity adjustment as there was an expectation on them to perform homemaking and caring roles (Tobin, 1996). These earlier studies also could all be described as a process of adaptation to chronic illness and reconstruction of identity. The negotiation of body, self and identity that people undertake when they experience chronic illness has formed a large part of Charmaz's work, and definition of the learning process as patients continue towards regaining previous notions of identity goals (Charmaz, 1995).

As the first GT study of medication-taking post AMI, this study adds to other more recent GT studies that involved a broader picture of AMI illness perception (Alsén et al., 2008), recovery from AMI (Petriček et al., 2015), and lifestyle adaptations (McKibbin & Wilson, 2001),(Dilla et al., 2020).

The grounded theory process modelling is produced as a result of organising actions and relationships, and in general terms could be described as an iteration of the experiential learning process (Kolb & Kolb, 2009) but it is the detail and context that this study adds that makes our findings useful, whilst moving from a description of the individual experience to a description that preserves the key factors within multiple individual's experiences, the outcome has more power towards generalisability. Grounded theory of the experience of illness has been described by Charmaz as thematically describing the changes to self and identity and also defining how patients manage their lives (Charmaz, 2016). In this study, there is a clear overlap with participants in dialogue with their bodily- and self-identities, and with the overall aim of continuing to live their lives and returning to their perceived 'normal' prior to having their AMI. With this in mind, perhaps a conflicting identity existed, as patients were aware of the chronic nature of AMI, and need to take medication for life, yet most aspired to a perceived return to normality, perhaps indicative of a revised new 'normal' where medication-taking didn't impinge on their lives.

The findings of this study have practical use in the context of medication-taking due to the closeness of detail and scale of both perspective and time. The first paradigm theme describes the process by which participants initially set up a successful medication routine and comes from rooting into location, timing and personal accountability. This category describes how participants manage their new lives and shows the high level of importance and concordance established by the hospital regime. Participants showed a strong belief of the need to continue the medication in order to benefit from the protection it offers, resulting from both their illness perception and dominance of healthcare system and cultural beliefs that their prescriber's directions are followed.

Participants indicated they assign high social status to prescribers, with other healthcare professionals used for emotional and information support. There was little discussion of shared decision making, yet this is stated by the NICE guidance for improving treatment adherence (Nunes, V, Neilson, J, O'Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009). Other healthcare professionals were underused for support, even though multi-disciplinary team collaboration is also recommended to assist patients, and therefore this suggests that efforts ought to be directed to improve their perceived role to provide knowledge, counselling and adherence support. This process model suggests that participants also consider the non-prescribing professionals involved in continuation of their treatment in a different capacity to those initially, and mostly used for the provision of medication, but providing information and social support only when needed at crisis point. Within community pharmacy at present, the opportunity for information exchange and side effect recognition takes place at treatment initiation stages through the NHS New Medicines Service (NHS England and NHS Improvement, 2021), with the service expectation that side effects and problems will present during this initial stage of treatment. As this study has shown, the requirement for medication change occurs spontaneously during treatment through the experience of side effects, indicating that a New Medicines Service isn’t the most appropriate form of intervention for this patient group, who require a treatment-long means of support and feedback system to prescribers. There is a need for improving patient education and relationships to offer support to patients at any stage of their treatment and outside of scheduled medication collection visits to the pharmacy or routine cardiac check-ups.

All the patients in this study claimed to take their medication regularly, rarely missing doses. Medication non-adherence has been classified according to patient type as intentional or unintentional whereby unintentional nonadherence has been caused by an external factor, such as memory or locality, and a patient has every desire to take the medication, but barriers in their life preclude them from doing so. Intentional non-adherence stems from a patient having made a conscious decision to not take their medication, influenced by belief and cultural practice related to their perceived need to take the medication (Clifford et al., 2008).

Whilst they described missing medication infrequently, none of the participants in this study expressed doing this intentionally, and instead describing non-intentional missed doses. They discussed unfavourable beliefs about their medications, and desires to stop taking them, but none missed doses as a result of their beliefs. This is similar to a cross sectional self-reported study of patients non-adherent to AMI medication (Park et al., 2020), where 70% reported unintentional nonadherence and 29% reported intentional non-adherence. The study found psychological beliefs and attitude contributed to unintentional nonadherence, and beliefs about medication the strongest determinant of intentional nonadherence. In this study, the meaning of a missed dose could differ between participants, and is not standardised and self-reported. It could mean a singular occasion, possibly overlooked in a narrative that is a generalisation of their experience, or a consistent avoidance for a period, for example when trying to figure out the cause of side effects. This highlights how important probing questions are to clarify meaning between interviewer and participants, and due to semi-structured interview coverage, may not have been fully expressed.

Within the participants interviewed in this study, there did appear to be a strong perception of the importance of medication-taking to maintain their cardiovascular health. Medication omission and non-adherence were rarely reported, so we cannot infer that this was an issue for this particular group. Therefore, the findings of this study are drawn from a group who are (or described themselves to be) adherent, adding to our knowledge of how successful adherence routines are formed, rather than overt non-adherence. These results could be a characteristic of the type of patients that we attracted in study recruitment, as observationally they were viewed to be helpful, educated and articulate patients. Similarly, by seeking volunteers, the study possibly recruited participants inclined to cooperative behaviours or had achieved sufficient distance and time to reflect upon their experience, and so were able to describe and share it. Perhaps patients who struggle or have given up with medication-taking similarly had no desire or means to share their story. Similarly, perhaps the recruitment process attracted individuals motivated to share an unrepresentative personal issue, either positive or negative, or to have documented a belief that they were passionate about.

As a qualitative study, these results could be cautiously extended to verify their applicability to larger groups of similar patients and no claim is made about generalisability. The use of UK patients means that the socioeconomic factors for this group of patients in this study may be less applicable to patients in other countries due to the unique form of healthcare system provision by the NHS.

The implication of work done by patients has been discussed and the time-related aspect of taking medication (McCoy, 2009). This study places this effort at the beginning of a patient's medication journey. This study found that following on from this effort, the adjustment set up and everyday life that appeared to require little effort from the patient.

For the third paradigm, bodily effects are recognised as side effects by patients, who then build evidence to bring to their practitioner. As found by a meta-analysis of this field (Piekarz et al., 2022), patients ascribe noticeable effects as due to medications and describe them as side effects. All participants deferred the decision to their prescriber, which is positive in terms of adherence, but also illustrates the power balance of the patient-prescriber relationship, and again indicates that shared decision making as suggested by the NICE guidelines have yet to be practically embedded into care practices, and multidisciplinary team sharing the work of patient support is lacking.

In summary, this study provides professionals with a model of how this patient group have successfully built medication-taking into their lived world, and offers practical information as to how they did so, such as attaching to existing routines, using times and locations as prompts, and planning ahead for non-routine activities.

This study has demonstrated that patients are constantly balancing up pros and cons of medication-taking and have a strong desire to continue taking medication. Medication beliefs are affected by discovering new information and experiencing new bodily effects, which may put doubt, confusion or cause anxiety to patients. Therefore, the requirement for knowledge and emotional support remains throughout the patient's medication-taking journey, and so healthcare professionals should continue to provide patient support and intervention opportunities ongoing, in addition to those offered in the early stages of treatment.

This theoretical process model shows that patients confer power and high status to prescribers, which may adversely affect their influence upon patients, and professionals ought to be aware of this when working with this patient group and consider how to improve patient-centred care in their everyday practice.

## Conclusions

This patient group had a strong requirement to adhere to taking medication, which they perceived as providing protection against a further AMI, with the overall aim to continue living and getting their lives back to ‘normal’. Participants described the three stages of medication-taking following an AMI; the setting up of a routine in their lives following discharge from hospital, negotiating the pros and cons but maintaining a routine leading to a stable state, and becoming overwhelmed by factors such as side effects that required them to ask their prescriber to make a decision about changing their medication.

This patient group described rarely missing medication, and built up a learned medication-taking routine through setting up timings, locations and attaching to other routines as reminders. They desired to follow the directions of their prescriber out of trust, debt and deference to the authority and knowledge of their prescriber. Patient involvement in treatment decision-making was infrequently described. Prescribers should be aware of involving patients in decision making at all stages, and of the power imbalance that is perceived by patients. Similarly, other healthcare professionals could become more involved in this process to devolve power away from a hierarchy around the prescriber, have more opportunities to provide interventions with patients and an integrated shared care relationship amongst the multidisciplinary team.

# Chapter 6: Narrative Analysis

## Introduction

Looking to the research covered so far, the constructivist grounded theory study has built a proposed model of the experience of taking medication following an AMI, that consists of a stage of building routine, balancing pros and cons, reaching a crisis point, and the aim of reaching a state of continued stability. The IPA study found that participants compared themselves to others, looked to the future, discussed their routine and missing doses, and knowledge was important for them. Again, both studies have few other studies in this patient group or methodologically to be comparable with.

The grounded theory study proposed a linear model, featuring a crisis point that led to a regression and reset, and literature was searched to find similarly shaped models. Little was found, but a narrative analysis of African-American patients taking medication for hypertension produced narrative arcs that were considered to be relevant to the result of our grounded theory result (Nakata et al., 2021). The arc shapes were applicable to our study, and so these were used to organise our results in a narrative analysis.

## Reflexivity

At the start of this study, while I could see that defining sections of the story into sections made sense, I was unsure that organising the arcs into substories would add to the result of the grounded theory, but very soon on, it become clear that narrative details were being added in addition to the narrative shape, which other analyses hadn't highlighted. I found it easier to manage this element of the study, while the sections were larger, they were fewer in number to organise. It was rewarding to see that each story arc could be clearly defined and also fitted within the overall narrative.

By this stage of my studies, I felt the supervisory oversight had eased, and I had been given more responsibility to continue on my own initiative. It was difficult to balance being proactive and applying new ideas, and knowing when it was justified to do so. I sought supervisory confirmation afterwards, and felt I was more confident yet still a novice researcher, and was open to being knocked back and amending my analysis. Here, applying my findings to those found in existing literature was a leap into the unknown, and I doubted whether I had made a presumption too far. In the end, as it worked, the result justified my doing so.

It was whilst preparing this thesis, and following my PhD viva feedback that asked the larger 'what does this mean?' question that I realised that all my participants considered themselves to be adherent to their medication, and so I could label them with this term, and change the discussion to become more than simple a description of the experience, but could define my participants better and their actions in taking medication in accordance to directions and thus 'medication adherence'. This went on to impact the findings and discussion of the results, whereby my participants were describing to me the actions and behaviours required to adhere to their medication, which is implied by the healthcare system and associated social groups such as cardiovascular support groups and also reinforced by personal relationships such as with family members.

# Paper D: A narrative analysis of the experience of taking medication to prevent a further heart attack

## Abstract

To enable a better understanding of the ideas, beliefs and factors that influence patients when taking medication to prevent a further AMI, the experience of taking medication was analysed using a narrative analysis approach to study the content of the whole narrative, and then the shorter narrative arcs were organised and then grouped according to themes. The whole arc analysis found that patients experiences were personal and detailed with individual meanings, but most participants discussed side effects as a complicating factor in their narrative. The thematic grouping of arcs found that building a routine was easy and quick process for participants, but they felt a lack of control and an identity adaptation whilst understanding the requirement to take medication. When balancing pros and cons, side effects featured prominently, but patient felt they had more control though knowledge and social support. A crisis point was reached when medication side effects became too much, and ultimately remaining stable was indicated by medication-taking becoming easy and unnoticed, with no change in medical monitoring. This allowed patients to continue living their lives, and remain at their current quality of life. These findings may assist with better understanding the factors involved with medication adherence, and thus inform clinical work with patients who may find these processes more difficult to build and adjust to.

## Introduction

Following an acute myocardial infarction (AMI), patients are given a life-long treatment of five evidence-based medications that are used to prevent further AMI events. These medications are proven to prevent patient mortality, reduce morbidity and associated healthcare system costs (Jones et al., 2013). In line with the general population, medication adherence in this patient group has been measured to be low; studies have found this figure to be 66% (Naderi et al., 2012). The World Health Organisation (WHO) has stated that medication adherence is a concern and issued the often-quoted statement that ‘increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments’(Sabaté E., 2003). Similarly, in the UK the National Institute for Health and Care Excellence (NICE) has issued guidelines to encourage adherence, which include patient-centred decision-making along with practical measures (Nunes, V, Neilson, J, O’Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009).

A Cochrane review of medication interventions for all disease states found that none produced significant improvement in adherence nor patient outcomes (Nieuwlaat et al., 2014). Within the all cardiovascular disease secondary preventative medication groups, interventions for adherence that have been found to be effective in improving adherence and clinical outcomes were a telephone short message service reminder which changed adherence to 65% in the intervention group vs 13% in the control group, a fixed-dose combination pill that showed adherence at 86% vs 65% in the control group, and a healthcare practitioner that measured adherence at 97% vs 92% in the control group (Fuller et al., 2018). The review suggested that long term studies are continued to establish how the interventions affect longer-term clinical outcomes.

Similarly, an analysis of UK-based randomised controlled trials that involved community pharmacist-based interventions to assist patients taking medication for cardiovascular disease found eight studies, seven of which improved medication adherence, and five of which indicated a trend towards blood pressure and cholesterol level improvement. However, these studies were deemed as poor quality by the research team. They request that further research be conducted to find the components that contribute to improving medication adherence, including designing an intervention tailored to patient’s needs (Al-Arkee & Al-Ani, 2023).

Medication adherence is a complex behaviour that is not fully understood. In order to better understand a patient perspective of medication-taking, a qualitative study is indicated, which help researchers to understand relationships, processes and patient beliefs regarding their medication (Renjith et al., 2021). Current intervention work is lacking in a theoretical evidence-base, and so research is often built upon presumed principles. In cardiovascular medicine, qualitative study is underused, yet could direct future work to assist patients (McIlvennan et al., 2019).

People use narrative and stories to retell their experiences according to their meaning-making of the event within the context of their lived world incorporating cultural and social aspects, which imparts their own beliefs, understanding, meaning within a structure that reflects the chronology of actions, power and status of the characters involved, and reflects their own perspective in the performance of the narrative delivery. Narrative analysis is a methodology that is used to obtain a participant's re-interpretation of an event or experience through their personal story, and in line with qualitative methods of analysis provides researchers a better understanding of participant's meaning and decision-making processes, their beliefs and values. In addition, narrative analysis focuses on participant's thoughts and emotions, aims, actions and consequences from their own point of view (R. L. Meraz et al., 2019) (Riessman, 2008) In particular, the medication narrative as a methodology has been used to bring together the personal act of medication-taking into the context of wider discourses about health and illnesses within a patient's lived world (Ryan et al., 2007).

In general, there is a lack of qualitative research in cardiovascular medicine, despite its potential to inform adherence intervention work and delivering targeted patient-centred care.

To deepen our understanding of the personal experience of this patient group, a method of analysis that examined patterns of story structures and political perspectives within this patient medication narrative would help us describe the experience for patients in terms of narrative shape and how relationships are portrayed. There are multiple methods and techniques used to obtain a narrative analysis, such as description by theme, structure or performance (Riessman, 2008). To deepen the focus our understanding of patient medication narratives, multiple methods of narrative analysis would offer researchers rich results (R. L. Meraz et al., 2019), with the aim to provide a deep and highly focussed practical lived-world representation, the scope of which could enable healthcare practitioners to direct intervention work with this patient group to assist them with medication adherence.

A study of medication-taking in this patient group that used grounded theory to define a process model of this experience found that there were three distinct elements within the story told by patients; building a routine ‘anchors away’, balancing pros and cons ‘nobody wants to rock the boat’, and then reaching a crisis point ‘man overboard!’, with the overall need to continue living and reach a state of ‘plain sailing’(Piekarz et al., 2023 – manuscript submitted for publication). Another study using narrative analysis of patients taking long-term medication for hypertension found that patient’s narratives took the shape of ‘out of the gate’, ‘fits and starts’, ‘existential turn’ and ‘slow climb’ (Nakata et al., 2021).

By using constructed grounded theory, a model is built by breaking down short thematic codes from the participant narrative, organising them into thematic groups, and then reconstructing a whole story using the relationship between codes as a joining and organisational principle. The study using narrative analysis used the participant story in larger sections of data comprising a whole story, which were then thematically organised. There is a clear overlap with the findings of both studies, and this current study will add to our knowledge by situating the data from the first study into the shape of narrative found by the second study. In the methodology of constructed grounded theory, the data is broken down into short codes containing units of meaning, often a phrase or sentence in length. Arguably, by coding in this way the bigger picture is removed from the story, and the reflected results could be extracted from the lived world described in the narrative. This study aims to fill this suggested information gap, and not only offer a more detailed understanding of the rearranged chronology of patient's experience, but also of lived world placing of the patient’s experience. This analysis will also remark upon the co- interpretation of meaning of story, and the participant and researcher’s roles in producing the narrative, which a narrative analysis is suitable to elicit. By using a narrative analysis will enable a comparison of the results of both methodologies.

This study will use the narrative as a whole, in order to maintain the real world elements, and aim to reduce the researcher influence upon the result (Mello, 2002), and then also break up the narrative into structural patterns; re-storifying, and then also organising the smaller broken up content of the narrative into typologies according to the classification headings of the findings of earlier constructed grounded theory work (Rolón-Dow & Bailey, 2021).

## Aim

To describe the patient experience of taking medication to prevent a further AMI using multiple techniques of narrative analysis to reflect both content and form of the narrative co-produced by interviewer and participant.

## Method

This study was reported using the Consolidated Criteria for Reporting Qualitative Data (COREQ) (Tong et al., 2007). Following Ethical Committee approval (UREC 18/36), promotional material was distributed to cardiovascular support groups in central and the south of England and also within the University. Inclusion criteria was that participants were taking medication for secondary prevention of AMI. Participants contacted the first author via email and were provided with an information pack. Fifteen participants, comprising five women and ten men, returned written consent and were recruited to the study, where they were assigned a pseudonym. Semi-structured interviews were conducted with participants by HP between 2019 and 2023, using an interview schedule designed to describe their experience of taking medication for secondary prevention of AMI (Kallio et al., 2016). Participants were offered the choice of interview at a suitable time and format of either in person, by telephone, or online. These were conducted in a quiet office. Interviews ranged in duration from 17 minutes for a pilot interview, which was included in the data, to 69 minutes, with an average length of 47 minutes. Interviews were audio-recorded to Mp3 file. The audio was transcribed to text using MS Word and verified by listening to play back alongside reading the transcript. The interview transcripts were returned to each respective participant for member checking as a form of rigour, and no participants wished to change their text, some expressed interest in the content. No incentives were offered to participants for their contribution, but effort was taken to offer then reciprocal gratitude, care and professionalism through all stages of their engagement with the research team (Winter et al., 2022).

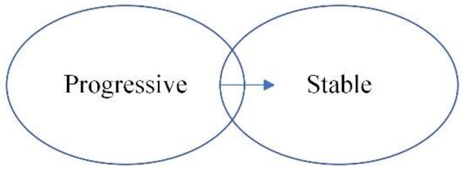
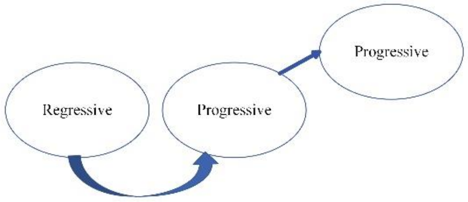
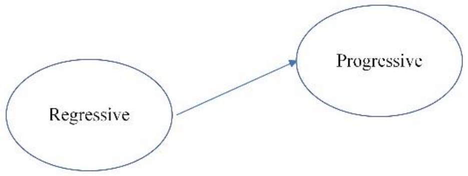
### Part 1: Whole narrative analysis

Transcripts of the whole interview narrative were interpreted by the first author, HP, for meaning and structural elements assigned, according to their purpose within each whole narrative (Labov & Waletzky, 1997); abstract, orientation, complicating action, evaluation and resolution of the story. As a question in the semi-structured interview schedule, medications taken were listed by all participants, and also descriptions of their AMI event were frequently included, but these were not included in the analysis, with the intention to focus on medication-taking.

### Part 2: Narrative arc analysis

Following this whole narrative analysis, the transcripts were divided into smaller story sections based upon the principle that the whole story consists of non-linear narratives, subtexts and digressions (Mishler, 1995). Each section was then placed into a narrative category according to features of shape of medication-taking narrative, by close comparison with shape of personal trajectory as described by the participant (Nakata et al., 2021),(Piekarz et al., 2023 – manuscript submitted for publication), as described in table 17.

Table 17. Summary of process stages of medication-taking and related narrative arc

| **Narrative category** | **Process stage according to Piekarz et al., (2023 MS submitted for publication)** | **Process stage according to Nakata et al. (2021)** | **Narrative arc diagram (taken from Nakata et al., 2021)** |
|---|---|---|---|
| 1 | Building a routine – 'anchors away' | Out of the gate |  |
| 2 | Balancing pros and cons – 'nobody wants to rock the boat' | Fits and starts |  |
| 3 | Crisis point – 'man overboard!' | Existential turn |  |
| 4 | Continued living – reaching 'plain sailing' | Slow climb |  |

All coding was done using NVivo 12 software to extract, group and organise this data.

These findings were then discussed and refined through dialogue with the second author, PD.

The results were agreed upon, and data organised into tables.

## Results

### Part 1: Whole Narrative Analysis

The structural elements of participant's whole narratives are categorised in Table 18.

Table 18.The structural content of participant's narratives

| **Participant** | **Category** | **Content** |
|---|---|---|
| Beki B | Abstract | Detailed expert knowledge, research and professional links. |

| | | |
|---|---|---|
| | Orientation | Working in collaboration with medical team on an equal level, does own additional research.<br>Husband's view is important, how she looks to him e.g. side effects, and comparison; he wouldn't be able to swallow meds. |
| | Complicating Action | Initial diagnosis unclear.<br>Presentation of side effects.<br>Planning, and then becoming pregnant.<br>Care for child. |
| | Evaluation | AMI was big event, worry in future |
| | Resolution | Try not to think about it, carry on with life |
| | Coda | Child is more important |
| Carl L | Abstract | Right. This is his presentation. Starting with Exhibit A: a medication list. |
| | Orientation | Medical and drug history from position of powerlessness and imposed passivity, self-study, dialogue with medical team, concern over medical motives. |
| | Complicating Action | Presentation of side effects.<br>Desire to improve above current; self-treat, learning.<br>Challenge of medical co-operation.<br>Discipline of new diet. |
| | Evaluation | This diet has changed the course of his life, puts all hope into it. Advocate for everyone to adopt it. |
| | Resolution | Health is stable; inferred due to diet. |
| | Coda | Modern diets are killing us. |
| Chris A | Abstract | Medical journey within context of his life and personality. |
| | Orientation | An entertaining version of happened, the characters in the medical team, and how they adapted their (plus wife's) life. |
| | Complicating Action | Changing doses, collaboration with medical team.<br>Prostate cancer diagnosis.<br>Wife's knee replacement.<br>Managing medication for other health issues. |
| | Evaluation | This is how we live, just get on with living. |
| | Resolution | Don't worry; life's too short, enjoy it. |
| | Coda | Having fun – 'We're just going out now in our Cabriolet'. |
| Colin B | Abstract | This was unexpected, but I dealt with it. |
| | Orientation | Following medical team directions. |
| | Complicating Action | Change to enteric coated aspirin.<br>Dose reduction of statins.<br>Private medical care; insurance payment. |
| | Evaluation | Private doctor; best care. |
| | Resolution | Returned to normal life, continued living. |

| | | |
|---|---|---|
| | Coda | Privileged life. |
| Gaye A | Abstract | She lives healthily. This was a shock. |
| | Orientation | Medical history, reflection on lifestyle, |
| | Complicating Action | Not being able to swallow medication.<br>Switching timings of statin to prevent nightmares. |
| | Evaluation | Follow medical advice, comply, get tips, keep healthy. Deduction that healthy lifestyle enabled her survival. |
| | Resolution | Disciplined lifestyle, has unanswered questions, but carry on with life. |
| | Coda | Passing on gratitude – volunteering in hospital. |
| Han S | Abstract | Did something different; on a clinical trial |
| | Orientation | Medical history; quiet compliance; ‘not rock the boat’ |
| | Complicating Action | Statin side effect.<br>Lansoprazole side effect.<br>Offered clinical trial. |
| | Evaluation | Carrying on as told. |
| | Resolution | Waiting for something to happen. |
| | Coda | Would blame medication if anything happened. |
| Lea S | Abstract | Begrudging compliance, clinical trial participant. |
| | Orientation | Takes with concerns; doesn’t get answers. |
| | Complicating Action | Specific questions – Why take blood pressure meds?<br>Why is husband’s statin dose lower than hers? |
| | Evaluation | Palmed off – on the correct meds. |
| | Resolution | Surgery are too busy, but trial nurse is sympathetic. |
| | Coda | Questions remain unanswered. |
| Maria U | Abstract | Fortunate in many ways |
| | Orientation | Other diseases and surgeries, managing through medicines |
| | Complicating Action | Side effects from statins, caused change<br>Stopped all meds for surgery<br>Other diseases being monitored and medications |
| | Evaluation | Carry on with life, fortunate, grateful |
| | Resolution | Make the most while you can, health gradually reduces with age |
| | Coda | Stay positive |
| Mark K | Abstract | Follows directions, appreciates medical knowledge |
| | Orientation | Listening, asks questions, follows advice. |
| | Complicating Action | Other diseases and surgeries.<br>Side effect of cough with ramipril. |
| | Evaluation | All working well, little trouble. |
| | Resolution | Working together with medical team. |
| | Coda | Appreciative of NHS skill and coverage. |
| Ola T | Abstract | AMI was a shock, but worked through it with support |

| | | |
|---|---|---|
| | Orientation | Other diseases and surgeries, other life accessibility issues. Problems overcome by positive attitude and social support, collaboration with medics |
| | Complicating Action | Multiple side effects.<br>Other diseases.<br>Illnesses affect lifestyle; mobility, driving issues. |
| | Evaluation | Getting on with what life throws at you. |
| | Resolution | Stay positive, keep active. |
| | Coda | Mental positivity. |
| Pat W | Abstract | Has multiple conditions to manage. |
| | Orientation | Functional, gets on with directions and helps others. |
| | Complicating Action | Surgery. |
| | Evaluation | Everything works well, teaching to pay forwards. |
| | Resolution | Follow directions, stay stable, live longer. |
| | Coda | Being helpful to others. |
| Phil H | Abstract | Discipline, follow directions |
| | Orientation | Negotiation, respect for medical expertise. Part of multiple cardiac issues. |
| | Complicating Action | Query about diagnosis.<br>Several hospitals communicating.<br>Expert on cardiomyopathy – advocate teaching role. |
| | Evaluation | Follows orders, has no problems that can’t be resolved by discussion. |
| | Resolution | Discipline. |
| | Coda | Knowledge and gratitude. |
| Rod F | Abstract | Had ups and downs, still testing new medications |
| | Orientation | Keen to return to fitness, health-minded, co-operative with medical team |
| | Complicating Action | Side effects with atorvastatin<br>Query side effect with Entresto<br>Little improvement in fitness as measure of health |
| | Evaluation | Appreciate requirement to follow directions |
| | Resolution | Has lived until this age, content. |
| | Coda | Helping medical professionals |
| Ron P | Abstract | Fits cardiac medication alongside diet, exercise |
| | Orientation | Self-care alongside medical team input |
| | Complicating Action | Side effects with simvastatin<br>Finding time to be active<br>Covid-19 restricting social activity |
| | Evaluation | Remaining stable, not noticing meds or lifestyle inputs |
| | Resolution | Whole picture of keeping healthy |
| | Coda | Looking forward to long retirement |
| Tony T | Abstract | Medicine is keeping his quality of life high |
| | Orientation | Follows medical direction, cares about how his illness is viewed by his family |

| | | |
|---|---|---|
| | Complicating Action | Episodes of atrial fibrillation<br>Severe side effect from rivaroxaban<br>Regular monitoring of conditions |
| | Evaluation | Medicine, diet and exercise contribute to health |
| | Resolution | Follow directions, remain in good health |
| | Coda | Health means continued living. |

All participants gave a detailed medication history as this was part of the opening sequence of the researcher's interview schedule, with easy to answer questions that were designed to open up the conversation. This part wasn't included in the categorisation, and neither was the background and course of AMI events that were also frequently given within the narrative as linked to the introductory questions.

The abstract for participants gave a description of what their story is about; often starting up with how this event was shock and imposition upon their life plans. It often offered a suggestion as how they personally overcame this. The orientation sited the narrative within a background of who did the actions, what happened and where, and therefore described similar elements for most participants, describing themselves as submissive patients on initial admission to hospital, who then became more knowledgeable with time, and collaborative in their relationship with the medical team. Some participants didn't feel that their medics listened to them but continued to begrudgingly follow medical directions. Several patients situated their AMI and medication within a life that featured other illnesses and their management also. They used positive psychological behaviours, research and knowledge, an awareness of their fortune or privilege and volunteered for novel treatments, which all propelled their narratives forwards.

The most frequent complicating event for participants was the presentation of side effects, and then medication timing or dosage adjustments. Participants often mentioned further illnesses adding complications to their narrative, and self-monitoring their cardiac health. Other family members took precedence in several cases, as a participant became pregnant and gave birth, or a partner's illness took priority over themselves.

Participants evaluation frequently summed up that they had reached a stable stage in their treatment, and could look back and reflect upon these historical events with a level of expertise. They also included a general reflection upon their health and lifestyle, and several people had used the events to help others by being patient advocates or educators.

Most participants described how they followed medical directions in their resolutions, ad adapted their lifestyle as a result of their AMI. They often inferred that taking medication, diet and exercise improved their ‘health’, and would enable them to live their current lives for longer. The resolution was often positive and hopeful, with the inference that trouble was in the past, and the future would continue in this present stage.

Again, the coda often included the activity they were presently or just about to do, and reflected what they had said in summary, an illustration of what healthy lives they led. Some participants looked to the future through their children or mentioned the diets of prospective generations. Again, most participants showed gratitude and considered themselves to be stable and in a state of continuing with their lives.

## Part 2: Medication-taking journey narrative arc analysis

The full table of narrative grouped by arc category types can be found in Appendix D, and the summary of narrative themes organised by arc category is presented in Table 19.

Table 19. Medication-taking journey narrative organised by arc type

| **1) Building a routine - ‘Anchors away’**<br>Out of the gate – *Progressive to stable* | | |
|---|---|---|
| **Summary narrative theme** | **Subcategory narrative theme** | **Narrative theme** |
| Lack of control | Medic action | Medic action to change medication. |
| | Medic action | Cardiologist takes action. With aggressive, battle talk against illness. |

| | | |
|---|---|---|
| | Medic action/ high status | All initial discussion was with consultant. |
| | Medic action/ Powerless | A shock to take in. Difficult but powerless. Medics have power, with hindsight has less trust in them. |
| | Powerless | Directive. Impersonal medication indicated on a card. |
| | Powerless | While in hospital, dominance of staff. |
| | Disorientation | Disorientated following hospital admission. |
| | Overwhelmed | Initially a lot to manage. |
| | Compliance | Told long-term, to prevent further AMI.<br>Nurse checking adherence, monitoring. |
| Routine building | Time | Timing prompt. |
| | Location | Location prompt. |
| | Adapt routine for changes | Set up a routine, amending required when away from home. |
| | Easy to adapt life/ compliance | Not taken anything previously, but easy adjustment, imperative to follow directions from medics. |
| | Organising routine | Uses a Dossett box, kept in the kitchen. Doesn't require further prompts. |
| | Organising routine/ adapting to change | Organised a system that works for him. Change of timing caused an omission, but soon changed again to a routine regular time. |
| | Easy adaptation/ amend for change | Adjusting to back at home, fitting it into a routine, is not an inconvenience.<br>Required planning ahead when going away. |
| | Organising routine / compliance | Organised, evidenced by record of BP. Follows medical directions. |
| Personal identity | Identity adaptation | Going from taking nothing to 'rattling' |
| | Identity change: negative | Awareness of being started on medication in hospital.<br>Started on clinical trial.<br>Never taken meds before, and unhappy about it. |
| | Environmental concern | Personal affront to environmental damage – drug packaging. |
| | Discipline | The Army formed his discipline. Aware of how his wife sees him if he misses dose. 'Finger trouble' - operator error. |
| Benefit to health | Benefit of taking/ family concern | Taking to avoid recurrence and improve quality of life to prevent symptoms of angina. Concern how his cardiac health affects his family. |
| Social requirement | Lonely/ sought knowledge | Lack of continuity of care, felt lost and fearful, same with husband. Sought information and learned for herself. |
| | Lost/ Social support | Unsure how to proceed, but worked it out. Social support from husband and daughter. |
| **2) Balancing Pros and Cons – 'Nobody wants to rock the boat'**<br>Fits and starts – *from regressive to progressive and to regressive again repeating* | | |

| **Summary narrative theme** | **Subcategory narrative theme** | **Narrative theme** |
|---|---|---|
| Self / choice | Personal responsibility | She’s responsible for coming off meds. |
| | Passive action | ‘Went back on’ Passive action. |
| Medic interaction | Medic action | Medical team make forceful decision, but she’s in good health. |
| | Medic collaboration | Agreement with medical team – ‘we’ acted. |
| | Negotiation with GP | GP convinces him to remain taking aspirin with a balanced argument for it. In spite of counterargument that at 76 it won’t prolong his life. |
| | Medic suggestion | Reversal- the guidelines have changed and GP wants him to stop aspirin. Reluctance due to perceived COVID protection.<br>Needs to work out how he will do so. |
| Emotional/ identity | Secondary care less skilled | Suspicious of GPs; busy, impersonal, lack time and specialist skill. |
| | Seeking help/ not answered | Query with GP about size (?)/ strength of medication, but GP ignores as it is the consultant’s decision. He feels frustrated. |
| | Perception by husband | Side effects affect husband – his view of her. |
| Missing doses | Omission not important | ‘Was prescribed’ passive.<br>Mitigating her meds omission.<br>Also it doesn’t matter. |
| | Omission not important | Missed medication is a memory issue, not bothered by it. |
| | Omission rare | Rarely misses doses.<br>Example of when intentionally stopped. |
| | Omission unnoticed | Doesn’t notice a missed dose, but if he did, then would seek info. |
| | Omission surprise | Missed doses – exclamation of surprise only. |
| | Omission not important/ understanding long term | Small dose omission doesn’t matter because it’s a long-term preventative. |
| | Omission not important/ understanding long term | Missing doses not a concern - considers a ’bank' of medication built up long-term. |
| | Omission not important | His concession to rebellion is to not worry about missed doses. |
| | Omission not important | Missed dose as out on an evening, chides herself but doesn’t care; at a rebellious age! |

| | | |
|---|---|---|
| | Routine change / omission not important | Being away from home can delay dose, can miss dose but doesn't worry, blames age! |
| Side effect tolerated | Side effect bearable / perception by husband/ knowledge of limited duration | Bruising almost intolerable side effect.<br>Worried how it makes her husband appear.<br>Limited duration mitigates this. |
| | Expectation of medication adjustment | Use GP to tailor medication to you, there's no time to do so in hospital. |
| Continuation important | Continuation importance / status of medic | Won't titrate heart meds like he does with other illness treatments, e.g., neuralgia; always follows cardiac medic's directions. Unquestioningly. |
| | Knowledge of duration / continuation importance | Lifelong medication, accept and continue with taking. |
| | Unnoticed taking/ continuation acceptable | Questions if they're working, but happy to continue with them. |
| | Side effects would seek help/ Continuation importance | If experienced side effects would seek help but wouldn't think of personally changing his heart medication. |
| | Continuation important | Wishes she did not have to take them, but accepts they are necessary. |
| Dose changes | Dose change/ adapt to life | Dose change of bisoprolol, at medic's suggestion, but takes when it suits him. |
| | Dose adjustments | Minor dose amendments, taking clopidogrel for longer than recommended, on consultant's advice |
| Change of routine | Adaption needs work | Change of routine requires extra work |
| | Adapt for change | Makes adjustments to routine to prompt taking if going out. |
| Knowledge | Knowledge / would seek help if change | Knowledge of side effects and would seek help if experienced them, just checking in with consultant for continuation |
| | Knowledge | GP answers his queries in writing. |
| | Knowledge | Continues to find information to answer her queries, asks GP. |
| | Status of medic/ compliance/ knowledge | Obeys orders. Status of medic is persuasive.<br>Informed himself over time. |
| | Knowledge / tolerates negatives/ long term benefit | Reads information, knows side effects. Tolerates negatives in hope of long-term benefit. Hope to keep the same by taking medication. |

| | | |
|---|---|---|
| Unanswered questions | Unanswered question/ comparison/ not answered | Questioning the strength of cholesterol tablet, comparing to husband. Ignored by medics. |
| | Unanswered questions/ theoretical | Side effects info is conflicting, doesn't check. He's not experienced problems |
| | Unanswered question/ side effect | Changed to Entresto, but query that it's causing side effects. Knows that it's expensive! |
| | Unanswered question/ side effect | Wants to amend the statin as believes it's causing taste and smell disturbances but doesn't say to prescriber. |
| | Query side effect/ benefit of taking | Queries if dry skin is worsened by medication, but offsets against benefit of taking. |
| | Desire to not take / perceived benefit / unanswered questions | We (plus husband) dislike taking medication; chemical substances. Built a routine and continue due to presumed benefits. Have unanswered questions that are dismissed by medics. |
| Social compliance | Desire to stop/ social compliance | Inspired by meeting man who stopped all his tablets, wants to reduce his medication, but social norm is to remain compliant and quiet. |
| | Forced compliance | Choice is limited, so need to take medication. Analogy of a broken car – prevention from dying. |
| | Compliance/ understanding long term benefit | Doesn't want to cause a fuss at GP. Makes a compromise to persist with it, balancing it with long-term benefit. |
| Seeking improvement | Desire to improve routine | He is stable but trying out a clinical trial to see if his state could be improved. |
| | Unnoticed working/ statins beneficial | Doesn't know if medication is working. Suggests statins are having only a good effect. |
| Economic implication | Financial implication | Health insurance stopped paying for Omacor, so covers the cost personally. |
| | Financial implication | Consultant advises fish oil, he skips dose if receiving dietary fish, for costs! |

**3) Crisis Point - 'Man Overboard!'**

Existential turn – *regressive turned right around to progressive and then further progress*

| **Summary narrative theme** | **Subcategory narrative theme** | **Narrative theme** |
|---|---|---|
| Side effect | Side effect | He's sensitive to drugs.<br>Side effect of fever from atorvastatin. |
| | Side effect/ medic action | Side effect of sore throat from ramipril.<br>Medics made decision. |

| | | |
|---|---|---|
| | Side effect/ medic action/ hospital supersede choice | Side effect of vein swelling from ticagrelor, horror analogy.GP stopped this medication, Hospital intervention to substitute back clopidogrel. |
| | Side effect/ medic action | Gastric irritation and bleeding caused by aspirin - consultant changed to enteric coated. |
| | Side effect/ medic action | Gradually stabilising, lansoprazole caused side effect of diarrhoea, and so stopped by GP. |
| | Side effect/ Medic action | Side effect of cough caused by ramipril; GP changed to losartan. |
| | Side effect/ medic action | Side effects caused by simvastatin, returned back to atorvastatin. |
| | Side effect/ collaboration with medic | Side effect of vivid dreams from statin, asked GP to take it in the evening instead |
| | Side effect/ collaboration with medic | Side effect of nightmares from atorvastatin. Built a case to bring to his GP, who changed to simvastatin |
| | Side effect/ collaboration with medic | Side effects of cough and vomiting. Worked alongside doctors and consultants to find cause and more suitable medications. |
| | Side effect/ collaboration with medic/ medic action | Side effect of leg muscle ache caused by statin. Stopped by consultant but given option to continue. Side effect of alertness caused by beta blocker, stopped by consultant. |
| | Side effect/ collaboration with medic | Varied dosages of bisoprolol. Too high, caused hypotension. Asked GP, who reduced dose. |
| | Side effect/ collaboration with GP/ hospital supervise | Side effect of leg ache with rosuvastatin, changed in collaboration with GP, together with hospital made change. |
| | Dose change/ addition to counter side effect | Passive ‘were changed’ dose reduction of statin, omeprazole to counter aspirin |
| | Side effect/ question unanswered | Asked GP about dizziness caused by Entresto. GP insists he remain on it to see. He needs to know for how much longer. |
| Seeking change | Philosophical argument crisis/ GP collaboration | Crisis – written to GP, came in person.<br>GP agreed to stop medication.<br>Considers he put GP in an unwinnable argument. |
| | Desire to change professional/ higher status/ unanswered | Wants to be reviewed by the cardiologist, but medical system dismisses her |
| Physical problem | Physical issue | Swallowing issues – takes with grapes |
| 4) **Continued Living – reaching ‘plain sailing’** | | |

| Slow climb – *regressive to progressive over time* | | |
|---|---|---|
| **Summary narrative theme** | **Subcategory narrative theme** | **Narrative theme** |
| Simplicity | Routine is normal | Routine is ‘just’, an accepted normal |
| | Addition to routine is easy | Adding medication is simple, addition to regular routine |
| | Routine is easy | Routine is an easy habit to maintain. |
| Unnoticed | Unnoticed taking/ monitoring | Medication review discusses timings, experiences no side effects |
| | Unnoticed/ stable | Doesn’t notice a benefit or change by taking medication. Remaining stable. |
| | Powerless/ continue without worry | Has no control over changing medication<br>Try and continue without worrying about future |
| | Monitoring/ continuation/ unnoticed | GP recommends continue – he's concerned about being overlooked |
| | Monitoring/ unnoticed/ waiting | GP reinforces that he’s been a good patient, worries about the effects of medication. Waiting for another symptom to present. |
| Stable | Stable/ waiting | No medication requires changing. Side effects take time, waiting for the next symptom to occur |
| | Stable | Has been stable ever since. |
| | Stable/ meds reduced/ continue life | No other incident happened. Some meds stopped. Aims to continue living. |
| | Stable/ not back to full ability/ attributes to ageing | re: Pacemaker and medication Remains stable, but expecting improved stamina. Presumes that ageing has reduced his ability. |
| | Stable/ waiting/ content | On a plateau – high up and level. Waiting for another symptom to appear, but happy now. |
| Biometric monitoring | Identity as healthy | Evidence that he’s extra healthy with cholesterol figure |
| | Routine casual/ healthy identity/ biometric monitoring | Medication appears a casual event, haphazard, but knows that its working through ‘OK’ results from biometric monitoring. |
| | Monitoring/ stable/ content | Regular check-ups across two hospitals, happy with stability. |
| | Monitoring/ stable | Regular monitoring by GP, signed off hospital care. |
| | Monitoring/ waiting | Continued monitoring. Watching biometric levels and aware if they change. |
| Fits into life | Routine fits life | Adapts medication taking to fit his life. |

| | | |
|---|---|---|
| | Importance of cardiac meds/ adopted as normal | Cardiac medication is different, and an accepted part of his normal life |
| | Routine is normal/ adapt for change | Routine is a repeated activity. Adjustments prepared for unusual activity e.g. a box in the car. |
| Satisfaction | Satisfaction/ collaboration with GP | GP and himself are satisfied, continue with current treatment |
| Ageing | Not back to full ability/ attribution to ageing | Reduced stamina, but accepts this as new normal, due to ageing. |
| Quality of life | Benefit to health/ quality of life | Taking tablets leads to good health. Self-care and following advice improves his health. Has had a long life, looking for maintaining quality now |

The four stages were a good fit for all the participant's narratives, with all participants describing all stages, except for Carl B, Lea S and Pat W, who did not discuss reaching a crisis point. In addition, Gaye A did not describe a stage of continuation.

The first stage, building a routine (out of the gate) was instigated by the return home from their stay in hospital. Participants described how they felt lack of control of their situation, from being in hospital where the medical teams were dominant and being overwhelmed by their current state. There was a strong urge to comply with medic's directions. At this stage they described feeling lonely, nervous and fearful, with a lack of transfer of care. Participants described how they organised a system in their lives to take medication which was often described as an easy process, and one participant mentioned they were previously taking medication, and added it to their regime. They arranged their medication in locations at home, fitting it into existing routines such as mealtimes and locations as memory prompts.

They described a change of personal identity being imposed on them as somebody who now had to take tablets, with negative connotations, but this suited the personality of one participant, where the requirement of discipline to take medication drew upon his practice in a military career and he viewed this as a drill. This change also conflicted with personal beliefs about environmental waste.

Participants mentioned how they began to educate themselves about their illness and treatment and found social support. They understood that treatment was life-long and taking medication would reduce their risk of another AMI in the future. Participants often mentioned they had been told to take their medication by their medical team, and there was an expected compulsion to take their medication by their healthcare professionals, and high status, trust and a fear of relapse of AMI caused them to follow directions.

The second stage, balancing pros and cons (fits and starts) was most a period where participants took back more control and worked in collaboration with their medics. They had more knowledge, about their condition and medication, recognising side effects that they experienced, but also participants decided that they would put up with a small amount of bother in order to receive long-term benefits. Some participants described stopping fixed duration medication or had strengths amended by their prescriber.

Participants also frequently had unanswered questions or desires, about whether the medication was working or side effects, but they didn’t act, or were dismissed by themselves or their prescribers, and continued with medication as they understood the long-term benefits of taking medication, and also a perceived notion that everyone quietly got on with taking medication, which was reinforced socially by medics and at cardiac rehabilitation classes. There was a general dislike of taking medication, seeing it as alien, or chemical, with a preference for treatment by what was seen as more natural methods such as dietary and through exercise. At this stage, also, missing doses was seen to be a negative blot on their ‘good adherer’ character, perceiving themselves as failing on this instance, but often blaming memory or human fallibility. In addition to memory slips, this happened as a result of being away from the participants' usual routine such as being on holiday or an unplanned activity away from home. However, there was a strong opinion across most participants that they were not concerned by single missed doses, viewing their history of continuous taking as a protective ‘bank’ built up.

The third stage, reaching a crisis point (existential crisis) was also reflected the majority of participant's narratives. This point was most often described when side effects became overwhelming or too troublesome to continue with. For a few participants these were described as acute and severe, but most placed the effects as inconvenient and a bother, such as muscle aches caused by statin medications. All participants shared details of their bodily effects with their prescriber, and then had their prescriptions amended. The majority of participants described their prescriber taking action, with them being passive. A smaller number of people described this as a collaboration, working suitable medication out together. A couple of participants also discussed that changes made by their GP were later amended or supervised by their hospital consultant.

Prescribers amended medication to another drug in the group, most frequently this happened with statin medication. Dose reductions also took place, which happened most often with beta blocker medications, such as bisoprolol. Some participants discussed being dismissed by the prescriber, and no change made, or being told to hold on and wait for more evidence. This frustrated the participants, making then feel not listened to or cared about.

One participant reached this crisis point by seeking an alternative treatment, gradually introducing a restrictive diet, and strongly urged their GP to permit them to stop most medications. One participant reached this stage by experiencing swallowing difficulties with medication and went to a pharmacist who gave advice.

The final stage of continuity was described by almost all participants as their current state. They described this as being simple, unnoticed and stable. They considered stability evidenced in biometric results, experiencing no symptoms, and that taking medication was easy and unnoticed; that they had reached a 'plateau'. Several participants added a caveat that whilst currently in stasis, that they were waiting for the next 'thing' to happen, be it a cardiac issue or medication side effect.

They were content, and considered that their lives were back to normal, desiring to continue at this stage. One participant wasn’t looking to prolong his life (he was 84!) but aimed to continue living his current quality of life. Several participants described their physical ability hadn’t returned to a previous level but attributed this to ageing.

## Discussion

This narrative analysis brought together the experiences of patients taking medication to prevent a further AMI, and whilst they described a narrative that was personal and specific to their lives, there were many features of their stories that repeated and were similar. All of their medication-taking journeys followed a similar narrative shape in a broad sense, that of introduction and adjustment to medication initially, reaching a level of stability, which could be complicated by the presentation of further cardiac events, side effects from medication, or other health issues presenting. Across all stories was the understanding that any changes that occurred were undertaken under the supervision of their medical prescriber. All participants discussed the requirement to follow or co-operate with the directions of their prescriber, and understood that taking medication would prevent a further AMI and was life-long.  They generally perceived themselves as stable in terms of cardiac health at present, and hoped that this would continue.

Using the initial whole narrative approach, narratives remained idiographic and personal, and retained these characteristics within the summary. This approach summarised the complete narrative and honed the text for the best fit for key structural points. Here, the narrative abstracts, evaluations, resolutions and codas showed the person within the world of their story, taking the researcher/ audience into their lived history, and ending with bringing them to their present situation and a reflection of the meaning of these events to them. Within the orientation and complicating actions, the participants described key factors which included the bigger picture of lifestyle and social relationships. Here, participants often described the relationship with the healthcare system or medical team as having a hierarchical power structure, and they were subjected to having less control of decision-making.

The whole narrative analysis illustrated the range of personal stories and interpretation of AMI events within people’s lives but could be limited due to the quantity of narrative covered in each case, and researcher interpretation of pertinent elements of text with precision to summarise the element. Therefore, it was also open to researcher interpretation influence. It was found to be a useful method to summarise and condense the text and locate each section within a long non-linear biography.

Using the whole narrative structural elements side effects were the most frequently discussed complicating factor in their narratives, with most participants experiencing these effects at some point. Other health events also complicated their narratives but were frequently viewed as secondary in terms of importance to their cardiac health. Only the event of becoming pregnant and having a baby caused the participant to place their cardiac health secondary to that of the prospective child’s. Of interest is how many participants mentioned going on to have a secondary AMI, but this didn’t appear in their narratives as a complicating factor, it presented as a recurrence, a biographical event but on the whole unremarkable in comparison to their first experience of AMI and subsequent changes that it imposed upon their lives.

From the orientation element, participants described their prescribing professional as a respected individual with high status, and therefore were compliant with the messages they issued. Of secondary importance, nurses and pharmacists were described as social support or intermediaries between themselves and their prescriber.

For the second part of this study, selecting narrative stages broke the story up into key points, but there was a greater quantity of narrative codes to include in a summary, and so the result is more precise for each stage, but also describes a greater range of themes than using a whole narrative summary.

The four structural elements continued to be a valid fit for these narratives. The most difficult stage to fit was considered to be the final stage of continuing stability, with the shape of regressive to progressive over time, and participants often ending their biographies in the present, it was more difficult to add a judgement on their present situation from the specificity of today within the context of the points that brought them here. The final element was a good descriptor of participants' whole narrative journey, but this wasn’t used for this part of the analysis.

This study builds upon the findings of a grounded theory study by this research team, which described these four stages, and concluded that the factors that were described by routine building could be used to assist patients for whom found this stage difficult. That study also highlighted the way that decision making was often removed from participants in the crisis stage, which contradicts the rationale behind patient centred care as a way of improving medication adherence.

In the grounded theory analysis, the narrative was broken down into codes, assigned according to chunks of meaning, and then rebuilt using the linking of actions, causality and relationships described. The grounded theory study provided a process model of the sequence of events, and their interrelation. In this narrative analysis, further detail is added to the grounded theory findings, due to the literal restoration of the story. The narrative become reordered according to chronology of events, and using whole sections of narrative adds back context, emotion and details such as timescales and personal feelings to give a richer, lifeworld picture of the ordered events.

In the narratives, missing doses was a frequent topic, as it was included in the interview schedule. The grounded theory study placed this within balancing pros and cons as a category. It was described by participants as rarely taking place, and of little significance. The narrative analysis adds further details, as participants viewed it as a human error, and often berated themselves for doing so, but did not consider a missed dose to be important, often balancing out a single event within a long history of successful medication-taking. This concept is important as it provides researchers with evidence how patients understand and conceptualise both missing doses and the act of continuing medication-taking, the event within the context. It also fits within narrative analysis research with angina patients, where it was found that medication-taking imposed a moral identity upon patients (Hawking et al., 2020). Similarly, here patients judged themselves to have failed by missing medication, with the expectation placed upon them by the healthcare system that they would adhere to given directions. Also, the lifestyle adaptation required not only physical life changes such as location of medication, but to take on the identity of ‘people who take tablets’, which was often incongruent to their perception of themselves. In one participant’s narrative this was a major factor that led to their crisis point, the imposition of becoming a person that relied on medication led them to find an alternative diet which replaced the action of medication in their view.

Alongside this medication identity change, participants linked this to healthy lifestyle identities, with diet and exercise improvement and continuation highlighted through this analysis. This was similarly viewed for its moral value as part of being ‘good patients’, but this was seen as a favoured practice than medication-taking.

However, these participants also described infrequently missing doses, and so could be considered as adherent patients, and may be less useful in terms of finding meaning behind non-adherence. Here, missed doses is non-intentional by participants, which may have a different causality than patients who intentionally non-adhere to their medication (Lehane & Mccarthy, 2007). It does provide researchers with an indicator of how these participants managed to build a routine by which they infrequently miss doses by embedding the action into their lives through location, timing and attaching to other established routines. Some mentioned that initiating this routine was easy to do, but no participants discussed experiencing a period of trial and error or a learning process taking place at this stage, which is often assumed. Current interventions to assist medication-taking are often based on the notion that adherence failure is a memory or routine-based issue, using interventions such as telephone prompts to assist memory or Dossett boxes to simplify regimes, but these did not appear to be regular issues for this group of participants. Similarly, the use of a polypill with multiple fixed doses of several medications has been tested amongst this patient group, but none of these participants mentioned that the volumes of medication were an issue, despite referring to their quantity as ‘cocktails’ and ‘rafts’ of drugs. However, the recollection of participants could be altered by positivity bias where the tendency to remember positive biographies is favourable, or fading affect bias, where negative memories are forgotten faster than those that brought about positive emotions (Crawford & Marsh, 2023), both as a form of coping mechanism to deal with stressful situations which could account for the absence of recall of a difficult learning process. Similarly autobiographical memory processes could be affected when participants are in a state of anxiety, as described by some participants in the early stage following hospital discharge, which may adversely affect their recall of the time (Marsh et al., 2019). However, for all psychological theories, their influence upon this work can only be speculative, as this is outside of the scope of this current research, and therefore the interview data we have available to us and acknowledge the epistemological assumption that is available to current team that this is a realist perspective.

The narrative analysis adds that participants often required social support at the initial stage of treatment, which they found in medical help from the advice of other patients and family members. They also received support through improving their knowledge and finding information. This knowledge also increased their awareness of side effects if they happened, they were able to recognise them and present them to their prescriber.

Most participants described that they experienced side effects, and this was placed into the stage of balancing pros and cons. The narrative analysis adds further detail that participants recognised these effects from having prior knowledge and information about their medication. When bodily effects were noticed, patients tolerated them until a point when they interfered too much with their lives.

This stage was then classified as reaching crisis point, ‘man overboard’ by the grounded theory analysis. Here, participants took the evidence to their prescriber and asked for a change of medication. Often this happened, and the prescriber changed the drug or reduced the dosage according to the type of medication causing the issue. The narrative analysis adds the importance of this finding as many participants described this as their prescriber acting on their behalf, with the responsibility of control taken away from them. This contradicts the ideas of patient-centred care and patients sharing decision-making about their treatment as detailed in the NICE guideline to support medication adherence (Nunes, V, Neilson, J, O’Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009).

The final stage of the grounded theory finding was continued stability, reaching ‘plain sailing’. In this narrative analysis, the added details that participants described it as being simple, unnoticed medication-taking, with no side effects and monitored using biometric results, they aimed to continue living their ‘normal’ lives, and one participant desired to maintain this current quality of life.

These narrative analysis findings are important because they show the patient-centred view of the process of this experience, and show how people adapt, learn and their accompanying ideas and feelings about this. It provides health professionals key areas upon which to engage and assist other patients who may find this process difficult, in the same way that these participants described the areas in which they struggled with. However, none of these participants described having any adherence issues, and so perhaps these results can only be viewed as a model of how to successfully adopt a medication-taking routine by this patient group. Along with this, the caveat that these qualitative results make no claim upon generalisability but could be cautiously extended to establish their applicability to other similar patient groups.

Several patients described that they were overlooked by their prescriber on experiencing side effects, and also having questions about their medication remaining unanswered, and this made them feel uncared for or ignored. Again, this is an area that this study has shown healthcare professionals could improve upon for delivery of patient-centred care. This also has shown that ongoing support is required by patients, and whilst is crucial at early stages and provided as such through cardiac rehabilitation programmes offered locally, indicates that perhaps a national system delivered via pharmacists could be useful for patients.

In this study, recruitment of participants took place through contact with cardiovascular support groups, thereby the majority of our participants theoretically have a support network, and perhaps this has benefitted them and assisted their adherence behaviours towards medication-taking. Similarly, by seeking volunteers to assist our research, we have self-selected participants with helpful, co-operative characters, which may also influence their behaviour towards following medication directions. Therefore, further adherence research should be aimed towards a more general population of this patient group, those who would admit to finding medication-taking difficult, or ideally the elusive group of people who don’t engage with healthcare systems.

This method of analysis has provided a detailed rich narrative of the process of medication-taking and has shown to be entirely complementary to the grounded theory study. From an ontological perspective, this works by both methodologies using time as an organising principle, and so the results will translate into one-another. The idea of narrative fitting into time was described by Thomas Mann in his novel set in a tuberculosis sanatorium, *The Magic Mountain*:

‘For time is the medium of narration, as it is the medium of life. Both are inextricably bound up with, as inextricably as are bodies in space.’(Mann, 1924) (p.541)

This novel was influential upon Heidegger’s ideas of the phenomenology of time and space (Jaran, 2021).

This combination of methodologies has also been found advantageous to breadth and depth of findings by other researchers (Nie, 2017), (Webb & Mallon, 2007). The first part of this study also fitted well into the second, again using chronology of story as an organising principle. This is resultant from the grounded theory process model that the research was based upon also formed a typical narrative shape, initiated by the start point being the start of the patient’s journey back to their home lives and adjustment that took place. The methodology that the grounded theory model used placed the coded concepts into a framework of causes, actions and consequences (Strauss & Corbin, 1998). Therefore, this is modelling the process of change, in the same way that all narratives are held together by a beginning, middle and end, usually with a logical change taking place between the start and end. Grounded theory studies using different methodologies where relationships between the concepts are not consequential upon time may produce process models that are non-linear, and this overlap of methodologies may be less useful.

The template established by the use of narrative arc upon the findings of the earlier grounded theory process model was a good fit, as in the semi structured interview scheme, participants answered questions, added anecdotes, reported stories and discussed topics in a non-chronological order.

## Conclusion

The four stages of the process model of medication taking of building a routine, balancing pros and cons, crisis point and reaching continuing stability were considered a good framework upon which to build a narrative analysis. This narrative analysis built upon previous findings to establish that building a routine was an easy and quick process for participants to establish.

Balancing pros and cons mostly involved medication side effects by which prior knowledge meant participants were prepared for and noticed their presentation. Missed doses were infrequent but were not considered important because participants considered themselves to be adherent and understood the need to continue taking medication. Missing doses was seen as due to memory failure and a momentary personal flaw in an otherwise ‘adherent’ character.

Grounded theory was a complementary methodology to narrative analysis in this case.

Healthcare professionals could use specific details found in this study to address issues for other patients, and also use the chronology of the stages to establish medication-taking journey models for other patients within a similar participant group.

# Chapter 7: Pluralistic qualitative approach

## Introduction

Following the three methods of analysis and the detailed finding described in the previous three chapters, this study combined the findings to determine if and how the combination of the results brought about additional findings.

The results of this study would achieve one of the research aims of this thesis.

## Reflexivity

Again, this was a difficult study to imagine how this would work in practice as little practical advice existed in literature, but the results were produced by the detailed overlaying of the separate findings by organising them into table which linked them by theme. As with the narrative analysis, the data was already presented, it required transposing and the key was to have a organising principle that I was confident with and trusting the method. Some themes were simple to place together by category, such as physical actions such as building a routine based around process, and the internal emotional work requirement to become the type of person who took medication. It also required imaginative thinking, and perspective shifting between perceptions, such as overlaying the idea of a continuity of medication-taking actions and linking this together with considering the future in a projection of themselves. Similarly, the identity shift between being the type of person who took medication, and also the person who considered themselves to be healthy was an interesting overlay, producing both an incongruence and also the requirement for belief adaptation that taking medication was a health-promoting behaviour.

# Paper E: The experience of taking medication to prevent a further heart attack: a pluralistic qualitative approach

## Abstract

To enable a better understanding of the ideas, beliefs and factors that influence patients when taking medication to prevent a further AMI, the experience of taking medication was analysed using a phenomenological, grounded theory and narrative analysis. The main findings of these results were summarised and compared. In addition to the singular findings of each method of analyses, points where methods produced thematic overlap added a perspective and deepened the area of interest, adding further meaning to the findings. The use of pluralistic methods produced a richer, more detailed analysis than that of the summation of findings alone.

## Introduction

In the UK, following an AMI, patients are discharged from hospital with a regime of five evidence-based cardioprotective medications to take. These secondary prevention medications are recommended by the National Health Service (NHS) in the UK as standard therapy in order to prevent recurrence of AMI, cardiac complications and rehospitalisation. High levels of adherence to each medication, and also to all medications, leads to improved cardiovascular event-free survival (Rasmussen et al., 2007). Adherence to medication is protective, leading to lower morbidity, and is associated with reduced hospital visits and healthcare costs (Plakht et al., 2020).

However, in line with all patient groups, they have difficulties adhering to their medication regime, Adherence has been measured to be 66% in this post-AMI treatment group (Naderi et al., 2012).

Poor medication adherence is a significant issue, prompting many healthcare organisations to focus work in this area. The World Health Organisation has issued a report, with the often-quoted line that improvement in adherence could be as important as technological advancements in drug treatment (Sabaté E., 2003). Similarly, in the UK, the National Centre of Health and Care Excellence (NICE) have issued guidelines for practitioners advocating that patients are supported by intervention work, which is grounded in patient-centred care, working alongside individuals to listen and offer support in ways that are tailored to their personal experience of taking medication (Nunes, V, Neilson, J, O'Flynn, N, Calvert, N, Kuntze, S, Smithson, H, Benson, J, Blair, J, Bowser, A, Clyne, W, Crome, P, Haddad, P, Hemingway, S, Horne, R, Johnson, S, Kelly, S, Packham, B, Patel M, Steel, 2009).

Interventions to assist people with medication adherence include non-specific aids such as medication reminders via telephone text messaging, or individual patient counselling such as motivational interviewing. A Cochrane meta-analysis of all medication groups found interventions have made a small contribution to improving adherence, yet none are universal nor significant, and further research ought to be directed in this area. (Nieuwlaat et al., 2014). To date, much focus has been in this field, yet little practical advances have been made. For secondary prevention of AMI patients, interventions have included a single fixed-dose polypill that contains multiple medications in order to simplify their regime, telephone messaging as a memory prompt with a 20% increase in adherence and direct patient information mail-out as an educational tool which had no significant effect upon adherence (Pandey & Choudhry, 2014),(Ivers et al., 2020). Similarly, individual AMI patient work with direct pharmacist counselling caused resulted in an AMI recurrence rate of 7.14% in comparison to 18.57% in the control group (Jiangbo et al., 2021).

Medication adherence is a complex multi-faceted behaviour which is not fully understood. Working towards filling this gap includes many proposed theories and behaviour change interventions designed to improve adherence (Easthall & Barnett, 2017). Within a healthcare setting, qualitative research is suitable as a method of obtaining a richness of data and depth of exploration in particular for humanistic and person-centred way of discovering about thoughts and actions of patients and their experiences (Renjith et al., 2021), and would be a suitable approach to further investigate the phenomena of medication adherence. In order to better understand the patient perspective of medication adherence, a qualitative study could inform researchers to provide an evidence base for directing work with interventions (Braun & Clarke, 2019). Qualitative study in cardiovascular medicine is underused yet would help us better understand the patient's perspective of their lived world practical experience of taking medication (McIlvennan et al., 2019).

Qualitative research uses various methods of data analysis, and choice is guided by the research question, theoretical framework and practical issues such as the type of data collected. In addition, there is currently interest in the development of multiple qualitative analytical methods, which are proposed to enrich the result by using several ways of viewing the phenomenon and therefore contain improved detail (N. Frost, 2011), and also maintain the clarity and richness of results, by avoiding reductionism (Kincheloe, 2001). There is also an argument that the plural and complex in ways that cannot be captured within a single analytical framework, and multiple methods moves results closer to those described by participants (Kincheloe, 2005).

This study proposes to use data the has been produced by this research team in earlier studies and combine to results to determine if and in what ways the synthesis of multiple qualitative methods improves the results obtained.

When undertaking a pluralistic study, from the outset, clear methodological choices are required about how the results will be presented, either as separate findings, or integrated, and choice of analysis method clear in methodological underpinning to understand the perspective lens being used, and also clear about the value of outcomes to current research (Clarke, Willis, Barnes, Caddick, Cromby, Mcdermott, et al., 2015).

This study will describe separately the findings of each method of analysis, based upon the findings from phenomenological, grounded theory and narrative analysis (Piekarz et al., 2021),(Piekarz et al., 2023 manuscript submitted for publication), (Piekarz et al., 2023 manuscript in preparation). They will then be overlaid where appropriate using a comparison and contrasting of each theme across each method. The results will provide a full map of categories and subset of themes described by participants in process of taking medication to prevent a further AMI.

## Aim

To use existing data to synthesise, using comparison and contrast to overlay the results of qualitative studies using phenomenological, grounded theory and narrative analysis to establish the effect of combining multiple methods and also description of result.

## Method

The data used in this study was given Ethical Committee approval by the University of Reading (UREC 18/36), and the Consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007) used to guide the reporting of the study.

Study participants were approached through the University and also through cardiovascular support groups in south and central England, with the inclusion criteria that participants were taking medication for secondary prevention of AMI. Promotional material was sent out by email, and enquiries were responded to with a study information pack and consent form. On return of informed consent, participants were invited to interview at a time and format of their choice. Participants were assigned a pseudonym. Interviews were conducted in person, on the telephone or online, using a quiet office. Interviews were audio-recorded to MP3 and were transcribed using MS Word into text format. Interviews were replayed and listened to whilst following the text to ensure correctness. Transcripts were returned to participants for comment as part of methodological rigour; no participants made comment on their texts other than expression of interest at what they had said.

A pilot interview took place, which was included in the analysis. For the phenomenological study, four participants were interviewed, and their data analysed using an interpretative phenomenological analysis framework (J. A. Smith et al., 2009). Following this, a further eleven participants were iteratively recruited to complete a constructivist grounded theory analysis and stopped when data saturation was achieved (Charmaz, 2006). Analysis was conducted concurrently with collection for this study in order to follow ideas and fill theoretical gaps. Following this, the same set of data was analysed using narrative analysis methods to describe the story structure and stages of medication-taking (Labov & Waletzky, 1997). The first author, HP, conducted all the interviews and analysis in each case, which was then validated by the second author, PD.

The original papers fully reporting the results of the phenomenological study, grounded theory study and narrative analysis can be found in earlier sections of this thesis, but for the purpose of this study have been summarised.

The findings from each of these studies were extracted, and for each theme or subset of categories was compared and contrasted between studies using  a mapping, appraisal and synthesis phases of meta-narrative as the methodological basis (Greenhalgh et al., 2005), and placed within the framework of the whole picture that built up and summarised according to structure and thematic detail.

## Results

### Phenomenological Analysis

The participants discussed that they compared themselves to others, knowledge of medication was important to them, they had assimilated medication-taking into their lives and that an upset to their routine made it more difficult to take medication. They considered the future as an unknown entity.

### Grounded Theory

Participants took medication for the overall purpose to continue living. This comprised three other stages; an initial stage of returning home from hospital and establishing a medication routine within their lives, the second stage was when they balanced the pros and cons of taking medication, compromising small problems in exchange for a perceived long term benefit, and then a third stage which could happen at any point was an existential crisis, which they required their prescriber to amend their medication in order to continue, which happened most often as a result of medication side effects.

### Narrative Analysis

The analysis of narrative structure found that participants tended to open their stories with a formal beginning list of medication, linking this to their leaving hospital, feeling of abandonment and disorientation. They overcame this through knowledge and social support. Separately from these feelings, they discussed their medication routine, stating that it was simple to set up and maintain prompts using location and other routines at home. They compromised concerns about medication with long-term benefits of taking but were also strongly compliant due to health care professional expectation, and high status that they assigned to their prescriber. They also discussed rarely missing doses, but most participants did not worry about this, balancing out the frequency of missed doses against a long history of continued taking. The narrative turned most often due to the experience of side effects caused by medication, which participants presented to their prescriber in order to request a change. Most participants ended their narratives by considering that they were in a stable position currently, and were looking to the future, mentioning continuing with normal life, and often with an expression of what they were doing now to illustrate this.

A summary of these findings is organised in table 20.

Table 20. A summary of the phenomenological, grounded theory and narrative analysis themes discussed by participants of their experience of taking medication for secondary prevention of and acute myocardial infarction

| **Grounded theory result** | **Narrative analysis result** | **Phenomenological analysis result** |
|---|---|---|
| Building a routine – ‘anchors away | Lack of control | |
| | Routine building | |
| | Personal identity – taking medication | Comparison to others: seen as healthy, incongruent with identity |
| | Benefit to health | |
| | Social requirement | |
| | Seeking improvement | |
| | Economic implication | |
| Balancing pros and cons – ‘nobody wants to rock the boat’ | Self/ personal choice | |
| | Medic interaction | |
| | Emotional/ identity – requiring to adhere | |
| | Changes of routine | Disturbance to routine: away from home, taking later |
| | Missing doses – unimportant, adherent identity | Missing doses |
| | Side effect tolerated | |
| | Continuation important | |
| | Dose changes | |
| | Knowledge | Knowledge: seeking and sharing information |
| | Unanswered questions | |
| | Seeking improvement | |
| | Social compliance | |

| | | |
|---|---|---|
| Crisis point – ‘man overboard! | Side effect – medic interaction | |
| | Seeking change from medic | |
| | Physical problem | |
| Continued living – reaching ‘plain sailing’ | Fits into life | Assimilated into their life: locations, systems, adaptations, unremarkable, unnoticed |
| | Simplicity | |
| | Unnoticed | |
| | Satisfaction | |
| | Biometric monitoring | Considering the future: requirement for certainty and reassurance, unknown |
| | Stable | |
| | Ageing | |
| | Quality of life | |

These results have synthesised the qualitative findings using three methods of analysis, and show that it was possible to fit all of the thematic categories produced by each method of analysis into one another, which added depth and detail to the sequential construct of the experience of taking medication following an AMI. Due to the large quantity and range of details obtained in each separate study, the themes have been summarised here for this purpose, and are illustrative for thematic comparison.

From the grounded theory analysis, a sequential model was produced comprising categories of building a routine, balancing pros and cons, crisis point and continuing stability.

During the building a routine stage, the narrative analysis added details that participants described having a lack of control, the act of setting up a routine, the change to their personal identity, they recognised the benefit to their health by taking medication, there was a social expectation that they would take medication, they sought improvement in their condition, and recognised there was a financial implication by taking medication. The phenomenological analysis added depth to the change to their personal identity category, where participants held on to and evidenced their healthy identity, and not seeing themselves as a ‘typical heart attack patient’.

In the next stage, balancing the pros and cons, from the narrative analysis, participants described having a personal choice, having an interaction with their medic, having an identity as person who took medication and their associated feelings with that requirement, they described a change of routine and missing doses, which was picked up by the phenomenological analysis and added further detail that missing doses happened when they were away from home or their routine, and that some doses were taken later than usual when they were reminded of their omission. In addition, missed doses were not seen as important by participants, and they balanced this against their ‘adherent patient’ identity where they usually took their medication. Participants had knowledge, and unanswered questions, and sought improvement in their condition, which was similarly picked up by the phenomenological analysis. Linked to their knowledge, participants noticed side effects at this stage, but tolerated them. They continued to understand the need to take their medication and described the social expectation to take medication. Here prescribers also amended strengths of medication.

In the following stage of crisis point, the participants decided that side effects had become intolerable and sought a change from their prescriber. This stage was also prompted by a strong desire for changing medication without the presence of side effects, and physical difficulty of taking medication. No themes from this stage were extracted by the phenomenological analysis.

The final stage of the process model, continued living, was detailed by the narrative analysis as fitting medication-taking into life, being unnoticed, and simple. This stage was similarly extracted in the phenomenological analysis, pinning the fit into routines, timing and location adaptation. Participants described they were satisfied at this stage. They also described this as having reached a stable stage, evidenced through biometric monitoring, attributing issues as expected from ageing, and discussed a desire for quality of life. This stability was reflected in the phenomenological analysis as considering the future, with a requirement to be reassured and have a certainty of their status.

## Discussion

These results show that by synthesis of findings, a deeper, richer result is produced, which could also improve the validity and rigour of findings.

The combination of constructed grounded theory and narrative analysis added linked themes extracted form narrative back into each stage of the process model. Then attaching the phenomenological analysis details back onto the themes, a further aspect of the themes was illustrated.

The grounded theory model was the basis of this synthesis which was a sequential model of the process showing the relationship between stages. By adding detail from the narrative, we have added back elements that were absent from the grounded theory such as description of the detail within themes for example, the participants described the building of a routine stage as easy and took little time to establish. Similarly, the narrative analysis highlighted social status such as the power and control relationships that medical teams imposed upon participants. The narrative analysis brough out emotions and identities attached to actions in addition to the grounded theory. The phenomenological analysis also added a dimension of depth to the detail, being situated in the personal, again such as adding in identity work, feelings and desires into the synthesis.

The combination of results was enriched by elements produced as a consequence of the ontological basis of each method of analysis. The constructed grounded theory broke down the data into small codes and rebuilt them according to the relationship and organisation of coding according to the basis of cause, actions and consequences. The narrative analysis consisted of two parts; the first detailing the ideographical detail across the whole story form each participant, and showed how each differed, but showed that social aspects and side effects were complicating factors across all narratives. The second part of the narrative analysis was included in this result and assigned the longer narrative sections described within each participant's story into a stage of the process model determined by the grounded theory result according to the shape of the narrative and extracted the thematic content at each stage. The phenomenological analysis added onto the thematic grouping by consideration of a close first-person perspective of these themes grouped again according to their content. No crisis stage was interpreted through this method of analysis, perhaps as a result of focus being in the close present, it was viewed as an event in the past that had been dealt with and didn't impact on participant's current perceptions. This method of analysis was conducted first, in order to prevent preconceived analytical influences from shaping the result, and this at this stage was considered to be beneficial to the findings, as the concepts of comparison of health identity and future thinking added another facet to the findings that threaded through initial, balancing ideas and continuity stages of the process model.

The link between grounded theory and narrative analysis was possible in this case as both analyses were underpinned by the element of time, having a clear beginning when patients left hospital having been started on medication, and subsequent actions such as knowledge acquisition, the appearance of side effects becoming meaningful after time has elapsed. There is an argument that after a first dose, that side effects could present immediately and knowledge could be acquired in minutes by reding a medication information leaflet. However, participants generally reported these events as taking place over time and punctuated their narratives with digressions when such events occurred along their biographies and so these actions were added chronologically. Grounded theory has produced the sequence of events, and the narrative adds back the dimension of time, and associated specific detail in terms of values (such as duration or ease of an action) attached to the codes, which may have been separated or not extracted from a grounded theory coding. Both narrative and phenomenological analysis added back internal emotions, identities and desires. The phenomenological aspect also was rooted within feelings and personal identity, and perhaps was more difficult to overlay within the stages, such as the comparison to others, which was attached in these results to the identity challenge work in the building a routine stage, but also crossed over into the continued stability stage where participants required evidence of their stability, their current 'normal' health status. Similarly this this overlap existed within the considering the future category, which was linked to chronology, and attached at the end of continued stability perhaps as it linked to a continuous implied future, but contained themes that were present at the beginning stages of medication taking such as notion of being told to take a medication forever, which overlapped many themes such as future thinking but also lack of control and affront to identity.

This result aligns with the concept of bricolage; the researcher is building a concept of a phenomenon with the best tools available to them at each stage, using multiple methods and diverse theories and philosophical perspectives of the elements encountered (Kincheloe, 2001). Here, each level of research adds a solid base to add and build upon, the result produced is weighty and uniform, in-keeping with the allegory of building an architectural construction, where the singular work adds a unique facet with a consistent alignment within the whole. However, in this result, the idea of identity and future thinking repeated across studies opens up a depth because they are presented in differing contexts. Participant identity within IPA was seen as not-identifying as the type of person who had a heart attack, but within the narrative analysis seeing themselves as having to adopt the identity of someone who took medication, and an adherent patient. The second theme that was opened up across results was the notion of future thinking, where within IPA participants recognised the future as part of their treatment, within grounded theory and narrative analysis the future was part of the final stage of reaching continued stability, and linked to prolonging live and quality of life. These areas of interest are a reflection of the analytic lens through which the data was seen, and open up channels through which the perspective of the phenomena can be viewed differently. This idea of opening up the result to different thinking is discussed as a form of abductive investigation within qualitative theory building, whereby researchers see the phenomenon in repeated ways, defamiliarisation with it and also recase it within a differing context (Timmermans & Tavory, 2012). Difference is embraced by bricolage also, where differences are not just tolerated within a result, but used as a spark for researcher creativity, and multivocality leads to a more sophisticated level of meaning-making.

This is the first known pluralistic study of medication taking in this patient group. A pluralistic study of self-harm using phenomenological, narrative and psychoanalytical analyses found again a rich result acquired from the building up of layers of analysis, while managing epistemological and methodological issues that arose (Josselin & Willig, 2014).

A pluralistic study of second time motherhood used discourse analysis, phenomenological analysis, grounded theory and narrative analysis, and found that each analytical interpretation of the same text added a different dimension to the understanding as a result of the method used (N. A. Frost et al., 2011). This study used different researchers for each analysis but agree with the findings that additional methods of analysis add a multidimensional aspect to understanding of a phenomenon, which differs from triangulation to reduce flaws, biases or analytic assumptions that could be encountered using a single method approach.

A meta-study of pluralistic studies agrees that this methodology opens up the possibility of exploring new ways of seeing phenomena by examining the tensions that arise by combining perspectives within the same study (Clarke, Willis, Barnes, Caddick, Cromby, Mcdermott, et al., 2015). In this study, the overlaying of realist constructivist ontologies fitted the grounded theory and narrative analysis together well, in a bricolage fashion, and the phenomenological study produced a perspective shift in particular around participant’s self-identity and their constructs of stability and future consideration that opened up further possibility for exploration of the phenomena of medication-taking in a way that didn’t happen with the individual study results.

These results shown promise as a useful practical method of showing thematic pattens across stages of participant's medication-taking process. It offers healthcare practitioners a model of stages of the medication-taking process, and accompanying theme categories to use as examples when working with patients. The rich detail and patient-centred results found using a phenomenological analysis method were more difficult to place within this model, but show themes again that could be useful when working with this patient group.

## Limitations

As these results are qualitative, they are not intended to generalisable, but indicate themes that could be applicable to other patients in this group. Similarly, all of these patients described that they took their medication and had formed a routine, so these results may be less helpful in working with patients who find this process difficult, but it does offer suggestions as to what a successful medication taking process looks like and suggests stages of this process at which patients could model their own journeys on. The details found within the stage could offer useful ways to consider addressing for patients in this group who find difficulties with taking medication.

Caution is required as within the phenomenological analysis, and whole-narrative analysis, the results were intended to maintain ideography, being highly detailed and case study specific. They are useful as they shown patterns on comparison but using them for this purpose forces the results into thematic summaries with a subsequent loss of detail.

In this analysis, a single researcher organised all the results, and also was the lead analyst for each original research study, and perhaps any assumptions and oversights have been repeated. The results have been validated by second researcher in all cases to reduce the impact of this effect.

## Conclusion

This pluralistic qualitative analysis produced a rich, detailed result, and added more than the sum of the single analyses.

This pluralistic method using grounded theory, phenomenological and narrative analyses produced a process model, with themes located and added value attached to these themes. Underlying this is a deep personal internal dimension of added meaning underpinning these themes, and appearing throughout the stages of this model.

# Chapter 8: Discussion and Conclusion

## Discussion

The pluralistic results of all three methods of analysis produced a rich, detailed result that added more than a single summation of the individual studies. For the purposes of overlaying the studies, thematic categories were used for representation of the combined results, but each study produced results that were highly detailed, specific and personal, of an exact level too great to be described fully here but can be found reported in the relevant chapter.

The phenomenological analysis produced thematic categories that showed participants compared themselves to others, knowledge of medication was important to them, they had assimilated medication-taking into their lives and that an upset to their routine made it more difficult to take medication. They considered the future as an unknown entity.

The grounded theory analysis proposed a process model that consisted of four key stages; building a routine, balancing pros and cons, crisis point and achieving continuing stability.

The narrative analysis overlaid onto the process model that when building a routine, participants experienced having a lack of control, arranged building a routine, understood that medication would benefit their health, and there was a social expectation that medication was taken. They recognised that they had an identity as someone who took medication, and also the financial implication of taking medication. By the next stage, participants described themselves as responsible for their medication, and were working with medics. They had more knowledge and could recognise side effects if they presented. At this stage they tolerated side effects, and also had dose adjustments by their medic to their medication. They infrequently missed doses, attributing this to memory and being away from their routine, but weren't concerned as they considered that they were most frequently adherent. They understood that continued medication-taking was important, again seeking improvement and following the social expectation that medication was taken. The next stage of reaching a crisis point occurred when side effects became intolerable, and participants required their medic to change their medication. This point was also reached by a strong desire to change medication, without effects experienced. Another participant experienced swallowing difficulties causing them to seek help. At the final stage of continuing stability, participants described medication-taking as effortless and unnoticed, viewing themselves as stable and we relooking to continue at this level, which was verified by biometric results, attributing failing ability to ageing and desired to upkeep their quality of life.

Through the phenomenological combination of this grounded theory/narrative model, several points remained such as the experience of side effects and the assimilation of medication into their lives, but two categories added a dimension of deeper understanding to the result; that of considering the future and comparison to others.

In the initial study, comparison to others was viewed as a means of asserting an identity of positive health by way of reassurance, but this study has also shown participants have a self-identity as good adherers as they upset this identity when they miss doses. This construct supports the concept of a healthy adherer that suggests some individuals who are likely to exhibit positive behaviours to healthy lifestyle measures are also similarly good adherers to medication, and this forms a bias that good adherers to medication show beneficial clinical effects which are partly attributable to their healthy lifestyles, and not just medication adherence (Simpson et al., 2006). As an aside, one of the studies cited earlier accounted for healthy adherer bias by measuring dose-related effects of adherence to medication for secondary prevention of AMI and included a placebo measure, and concluded the reduction in mortality by adherence was drug class specific (Rasmussen et al., 2007). Continuing the comparison to others identity into continuing stability, this also echoed in participant’s requirement to measure their ‘health’ status, and confirm their stability, and this then fed into the construct of considering the future, as maintenance of health was implicated in their personal longevity and quality of life.

This duality opens possibilities for a deeper understanding of participant’s experience, described in other pluralistic studies as the creation of analytic tension, which then becomes a feature of interest for further study. The production of multiple identities through overlaying of qualitative findings has been discussed as fluid identities and multivocalities opened up by this work increase possibilities rather than conventional reliance upon restrictive single paradigm models (Lincoln et al., 2018).

In this study, the combination of qualitative methods was viewed to complement one another, and both fitted the research question and the ontological features of results enabled the finding to be overlaid. There remains a question as to the level of categorisation and ordering that takes place in order to present results. For instance, the phenomenological results are intended to be seen as highly detailed case studies, and to become more summarised to produce thematic categories for use in pluralistic study, that personal detail has been lost.

As these findings are qualitative, they can be cautiously extended to see their applicability to other similar participant groups, but again with the caveat that they are not intended to be generalisable, and again as mentioned above, were highly individual suggesting that a person-centred approach is appropriate for clinical intervention work. Quality measures were upheld through this research, for both individual studies using standards for each methodology as described in the relevant chapter, and across studies, and include that a single researcher analysed all the data, and the data was the same for each analysis, except for a smaller data set used for the phenomenological study.

Whilst this thesis has worked towards finding summaries and grouping ideas and experiences into themes, an important finding is that while themes, patterns and processes were present, for each participant they were very individual, personal and meaning of these concepts differed between participants, such as their own concept of their good health. This suggests that whilst this study offers areas where healthcare professionals can focus upon to assist patient adherences, a one-size-fits-all approach and generalising a single intervention is not appropriate. This study’s findings suggest that individual work with patients and tailoring the interventions to their personal needs is the preferential form of support in assisting this patient group. This aligns with the NICE guidance CG76 to support medication adherence in that a patient-centred approach ought to be taken to help people to take their medication (National Institute for Health and Clinical Excellence, 2009).

From the earlier systematic literature search, these findings agree with the idea that the experience of medication taking was personal and specific details were important to individuals. The coverage of themes found over the course of this research was touched upon, but due to the small amount of literature found, the overlap with these findings is thin and varied. It indicated that this current research has filled a needed gap in knowledge, and is the starting point for further work to address the issues of non-adherence in this patient group.

As repeated through these chapters, and elicited through the ongoing process of reflexivity during this research, the findings describe the participant experience from people who considered themselves to be good adherers, and so offers researchers a description of the behaviours and thoughts of participants who had successfully taken medication regimes into their daily practice. If the ultimate aim is to assist in our understanding of non-adherence, it may be a step towards this, as this contributes to our knowledge of this experience in this particular patient group. These findings could also have a clinical application as they model the factors that influence patient behaviours and could be used to assist themes and development of interventions that may help patients who find adherence difficult. While noting that this research studied the experience of participants who intended to adhere to medication, and may not apply to patients who do not want to adhere to medication, described as intentional non-adherence, where other beliefs and factors may affect patient actions. In our study, this patient group described circumstances when they missed medication and were non-adherent due to unintended factors.

It is important to note that the participants recruited to this study described having taken their medication for an average period of ten years, ranging between three and twenty years since their initial AMI. Therefore, our participant group may be representative of patients who have achieved stability and continuity of adherence, and those in the initial stages of less than three years since their AMI may still be routine-building and finding difficulties with the process of adherence, and may report different factors that they are in the midst of experiencing without the benefit of prior knowledge or hindsight that our participants reported. Of importance in this research is the finding that participants experience of reaching a crisis point took place all along their medication-taking journey, and participants requirement for clinical support was not related to time-duration; it could happen at any time. Therefore professionals ought to be aware that throughout primary care, patients may require medication changes and be prepared to do so, and similarly pharmacists and allied professionals may receive requests for assistance from patients at any time. Currently, in the UK, in addition to the freely available support for patients with queries within community pharmacies, the NHS offers two pharmacy services designed to assist patients in taking medication, situated at stages where extra support is required. These services are the New Medicines Service, where patients are offered an initial consultation then follow-up to discuss a medication at the beginning and early stages of taking a new medicine within targeted disease groups. The second NHS pharmacy service is a Discharge Medicines Service, which offers patients further professional care at the early stages of transfer from a hospital setting back into their homes and community setting. Both of these services are skewed towards helping patients in the initial stages of starting a medication, or returning home with medication following a hospital stay. In addition, pharmacist services are also provided within GP surgeries, and are closely linked to prescribing and medication management, where surgery medication reviews take place annually with patients, and enable close monitoring and follow-up of changes to medication. The findings of this research agree that participants discussed these early periods as times of difficulty and a cause of anxiety, and so assistance at this stage is justified. However, this research has also shown that help is required throughout the duration of treatment such as the experience of side effects or internal conflict reaching a crisis point which take place sporadically, indicating that support services ought to be available to patients throughout their treatment, again placing surgery-based pharmacists in potentially an ideal position to assist at this stage. Highlighting the availability of the pharmacy profession as being an ideal location to offer ad hoc help such as this. This also fits with the evolving profession of pharmacy, with the change to incorporate a prescribing qualification into the current education and training to become a pharmacist, more prescribers will be working in directly patient-facing roles. It is yet to be decided how this will work in practice, but potentially offers patients open access through pharmacy to a prescriber who could amend the strength, change medications and also speed up the triage process to refer patients onto a medical prescriber if deemed necessary. All of these interventions work towards supporting the patient experience by improving access and speeding up the process to support medication-taking. This thesis has validated that medication management assistance and information provided at the early stages of treatment are useful to support patients by providing knowledge and social support. However, as described above, the stages of balancing pros and cons and coming to a crisis point continue through treatment and is not duration-related for many patients, suggesting that support provided by pharmacy services and cardiac rehabilitation ought to be revisited through the continuation of medication. Similarly, this study has shown that patient beliefs and knowledge about their medication feature strongly in their adherence behaviour, with ideas that medication offers them protection, and their accumulated adherence behaviour was important for their continuing perceived level of health.

This study has also shown that while there are many medication-related issues that patients experience when taking their medication, such as side effects and timings, there are also many more that they described relating to personal beliefs and conflicting ideas, such as their health identity both within their personality and outwards in comparing themselves to others. Therefore the assistance of allied health professional such as behaviour change specialists is indicated to help with these ideas of behaviour change. Pharmacists have assisted in this type of work to support patients in collaboration with psychologists through the process of motivational interviewing, and this research suggests that this could potentially assist similar patients with medication-taking issues.

Similarly, this study has shown that patients consider their medication as part of a larger health and lifestyle picture that affects and is affected by their medication-taking. It indicates the importance of the multi-disciplinary team when working with this patient group, not just the medical team, but pharmacists, psychologists, and more social-focussed professionals such as occupational therapists who could all professionally assist in the adjusting a whole lifestyle to taking medication for secondary prevention of AMI.

The use of interview data has limitations, as the findings are self-reported by the participants, and therefore trust that they are an accurate representation of the real experience of the participant. Similarly, interviews are subject to their own biases due to power structures and social formality both between interviewer and participant and perceived healthcare professional or academic status of the interviewer, which may have influenced the participants to provide answers to make themselves be viewed as a ‘good patient’ (Anyan, 2013). Interviews remain a valid and useful method of collecting data about personal thoughts and experiences, and the use of enhanced cognitive interview in this work has aimed to reduce this factor in the data obtained. In this study, participants were keen to describe themselves as good patients, and most described how they successfully took their medication, perhaps as this was the implied expectation from the research team, both culturally in originating from a healthcare department, but also the invitation to participate in the study was for people who take medication, perhaps to the exclusion of those who didn’t successfully achieve this in practice.

These findings may also be limited by the behavioural nature of participants that we recruited, by seeking volunteers, perhaps the study attracted participants of a helpful, compliant nature. Also the selection of participants using cardiovascular support groups again may have tended towards individuals with a healthy support network, knowledge and education and the influence of other socioeconomic factors that are less prevalent in a more general population. As noticed in our data, several individuals were attracted to participate in order to share an issue that was important to them, such as the adoption of a radical diet, and being a participant in a clinical trial, which again, could perhaps be illustrating participants with more proactive behaviours. Again, the findings of this study is not intended to be applicable to more general groups of patients, but carefully extended for comparison to other similar groups. Here, a detailed background of the socioeconomic and cultural background of participants was not taken at their recruitment, which is a shortfall, as we do not know this detail for the purposes of reproducibility and accountability. This absence of participant demographics limits the detailed description of our participants, and so we can only claim these findings to be applicable to a general population within our selection criteria, as opposed to a more specific group. This could also be a strength of the findings as while not recorded, this shortfall implies that our population came from diverse range of backgrounds as we were not selecting for socioeconomic nor cultural demographics and therefore our results could claim variety of detail and depth of the result produced across all participants. In a similar way, the aim of this study was to produce a descriptive report of the themes produced when patients take medication for secondary prevention of AMI. The study did not assess the participants for categorisation of their level or type of adherence to this medication. As a result, we cannot imply that non-adherent participants find the opposite difficult, as adherence and non-adherance are not dichotomous, and the behaviours involved in medication adherence may not be relevant to non-adherent participants. Indeed, as discussed in the introduction, measurement of adherence is arbitrary according to a standard 80% measure of medication taken, for the purposes of research and study. In this thesis, participants described missing doses which would be classified as non-adherent behaviour, but everyone interviewed discussed how they refilled their prescriptions and had every intention of taking their medication, placing them in the category of non-intentional non adherers. Whilst participants described missing medication infrequently, none of the participants in this thesis expressed doing this intentionally, and instead described non-intentional missed doses. They discussed unfavourable beliefs about their medications, and desires to stop taking them, but none missed doses as a result of their beliefs. This is similar to a cross sectional self-reported study of patients non-adherent to AMI medication (Park et al., 2020), where 70% reported unintentional nonadherence and 29% reported intentional non-adherence. The study found psychological beliefs and attitude contributed to unintentional nonadherence, and beliefs about medication the strongest determinant of intentional nonadherence. In this thesis, the meaning of a missed dose could differ between participants, and is not standardised and self-reported. Missed doses were personal in terms of the cause attributed, the significance of its meaning, and also situational both upon life aspect and in specific moments, such as being lost or confused, or away from the home.

This research forms the basis of further work in understanding medication adherence in this non-intentional non-adherent patient group. It has also highlighted distinct stages in the process model, which could enable researchers to map out behavioural features within each stage. Similarly, further work could be aimed at longitudinal studies, with more focus on chronology of behaviours. All of the participants in this research considered themselves to be at a stable stage in their medication-taking, and perhaps future study could focus on participants who are actively within an earlier stage, and perhaps closer in time to recall the experience as it is current to them. In this study, participants had observationally described having taken their medication for an average period of ten years, ranging between three and twenty years since their initial AMI. Therefore, our participant group may be representative of volunteers who have achieved stability and continuity of adherence, and those in the initial stages of less than three years since their AMI may still be routine-building and finding difficulties with the process of adherence and may report different factors that they are in the midst of experiencing without the benefit of prior knowledge or hindsight that our participants reported. Similarly, we are also selecting for survivors as participants who took mediation inherently have reduced mortality from AMI, and therefore longevity of experience of taking mediation. The finding that non-adherence in this patient group falls into different longitudinal pattern categories who could be grouped into those with fast decline, slow decline, occasional users and initial gap followed by increased adherence (Lip et al., 2023). This aligns with the idea that several types of behaviours contribute to patient non-adherence. Many of the participants discussed also taking medication for other diseases; approximately half of the participants mentioned that they were taking medication for other chronic illnesses, and around half of those were cardiac-related linked to their AMI, such as atrial fibrillation or angina. Again, in literature patients taking greater numbers of drugs were more likely to be adherent (Shang et al., 2019), yet those with co-morbidities were also found to be less adherent, possibly with a link to poor education. In a study comparing drug classes and secondary prevention adherence, patients with ACS co-morbidities such as peripheral vascular disease and hypertension were found to be less likely to discontinue taking their medication (Akincigil et al., 2007).This is a limitation of our study, as other co-morbidities were present in many of our participants, so we cannot claim that these factors arise simply from taking medication to prevent a further AMI. However, this is a real-world reflection by our participant group, and also observationally participants discussed that their AMI medication was always their priority, and other medications were 'less important', such as eye drops or inhalers.

In summary, this research has shown that the patient experience of taking medication for secondary prevention of AMI could be classified into themes, the details of which have been discussed above, which also fit within factors associated with medication adherence, such as patient and medication related factors. The level of detail is important because it illustrates factors related to medication that are specifically experienced by this patient group, where issues such as side effects are often experienced by patients. However, this study has shown the coverage of these themes to be detailed and personal, indicating person-centred individual work to assist medication-taking for this patient group. Pharmacists are an ideal starting point for this work beginning at medication, but we have also shown how much personal belief and life world factors are important to patients, indicating that a whole multi-disciplinary specialist team such as psychologists and occupational therapists in collaboration would further assist patients in building good adherence behaviours. This team should also be available to patients throughout the course of their medication-taking journey, whilst agreeing that the support offered at the beginning of their journey is also important for providing knowledge and personal development.

This thesis offers researchers starting points of general themes and more detailed factors involved when patients take mediation for secondary prevention of AMI. As indicated for future focus in research, these themes could assist in the development of personal intervention work, such as preparation for experiencing side effects, and building medication routines within their personal lifestyles. The themes found here offer researchers evidence-based themes upon which to build further quantitative focused work to assess how these factors assist medication adherence in this patient group, and the creation of a practical intervention that could be of use in working with this patient group. This thesis also offers a methodological blueprint for other researchers to use multiple methods of analysis to study the personal experience of any phenomena as here the multiple methods of analysis were found to deepen and offer a better description of the findings. Researchers could use this plural methodology to be able to study other patient groups’ medication taking experience to better understand the feelings, actions and processes involved for them.

To take this research forwards, future studies could build upon this work by better defining the type of participant involved and organising them into adherers and non-adherers, and focusing upon intentional and non-intentional non-adherence, which again as discussed earlier is an arbitrary description and is itself problematic in its definition such as deciding the boundary to be 80% adherence as measured, or a self-defined term by patients. In future work also, improved socio-demographic data recording could assist in better defining and describing the participants being investigated, which would assist moving towards claiming generalisability of findings, or making more specific claims within socio-demographic categories within the patient group.

Also as described above, this thesis has provided a snapshot of the patient experience, where the participants had been taking medication for many years previously. It has found distinct stages to the patient process of adherence to medication-taking, and further work that focuses on contemporary early stages of adjustment behaviours and patient requirements would be appropriate. Similarly, a longitudinal study of a patient cohort through these stages would also be appropriate further work.

Through this thesis, I have personally acquired skills in multiple methods of qualitative analysis, and their combination, and would like to take these further in developing other methods of analysis that I didn't use here, such as conversation and discourse analysis. I would also like to further study the pedagogy of the methods and their theoretical and philosophical basis in order to better understand the positionality and ontology of how each method is working, and understanding of what happens when the findings are superimposed in a plural study. I also wish to take this work forwards, and work with patient groups in more primary care settings, perhaps situating my work within a clear healthcare organisation, as opposed to working here with voluntary community-based groups.

On a final note and point of reflexivity, whilst searching for guidance on compilation of a PhD by publication, the concept of Kincheloe's bricolage came up in its original field; the subject of education. Here it was used to illustrate the idea of a thesis by publication as being greater in intellectual content than the sum of the papers contained within it (Niven & Grant, 2012). They argue that a thesis by publication is more powerful when that set of papers are backed with clear context such as a detailed introduction to add to the research aim, and that the papers are relevant to that aim and build upon one another towards that aim.

Therefore by serendipity, this thesis by publication is a *meta-metaphor* for the pluralistic methodology used (Morowitz, 1998). In the same way that this thesis has achieved its research aim through its clearly justified content and building context around each research paper, here the pluralistic analysis has achieved this also by building upon the paper previous to it, in methodological choice, even for example, the IPA analysis findings weren't used as a basis for the grounded theory analysis. Here, each method of analysis built upon one another by clear and justified choice of methodology, and finally was used together to draw on all the previous findings and knowledge within the context of each study. In this way, the pluralistic result produced more information and deepened our understanding more than summation of the singular result of studies alone.

## Conclusion

This thesis aimed to be able to describe the experience of taking medication to prevent a further AMI, and if using multiple methods of analysis added to our knowledge of this experience.

The systematic literature search confirmed that current research was thin and disparate in its coverage of this patient group using these methodologies, and validated that our research aim would fill a current gap in our understanding in this field.

The phenomenological study found that participants described that they considered the future, compared themselves to others, built a routine and described when they missed doses, and that knowledge was important.

The grounded theory study found that the process involved four stages: building a routine, balancing the pros and cons, reaching a crisis point, and continuing stability.

The narrative analysis found that participants stories were varied and personal, yet most featured the presence of side effects as a complicating factor. This analysis added to the grounded theory stages and found that participants build a routine quickly and easily, and weren’t concerned by missing doses, as they balanced out the protection offered by their history of continued taking doses.

The pluralistic qualitative element added to our understanding by adding a depth of perspective in several themes such as participant identity and future thinking.

These results offer thematic categories for future work in studying how participants achieved medication adherence, and may help suggest how poor adherence can be overcome. The highly detailed and specificity of results indicate that person-centred work is appropriate for intervention work by healthcare professionals.

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# Appendices

# Appendix A: Participant Information and Consent Form

## Information and Consent Form

25/11/18

## Background

**We are interested in studying the thoughts and experiences of people who have been given medicines to protect their heart after a heart attack. This can include medicines like aspirin, clopidogrel, statins, diuretics ('water tablets'), amlodipine and losartan. We want to do this study to better understand what the experience is like, and what helps people take their medicines and what stops them.**

I would like to invite you to take part in my study to better understand from you what it is like to be prescribed medicines following a heart attack. We are contacting you as you will have recollections and thoughts that are of interest to me.

## Why is this study being conducted?

I am conducting this study as a part of my Pharmacy Practice PhD project at the University of Reading. Through this project, I hope to learn what your experience of taking heart medicines is like, and the things that help or stop you taking these medicines according to the instructions. From this study, health professionals like pharmacists can be given better ways to support patients who take these medicines.

## What is involved if I agree to take part in this project?

If you are interested in taking part in this study, you would talk to me in an interview either on the telephone or in person at the University of Reading. I would ask you to agree for me to audio record the interview. If you'd like to take part, please contact me through email: h.piekarz@pgr.reading.ac.uk, and I can answer any further questions you may have. If you decide to take part, the consent form for you to sign is found at the end of this letter. I will arrange the meeting at a time convenient to both of us once you have sent me a signed copy of the consent form.

During the interview, I will run through this information letter again and then I will ask you questions about your views and experiences of taking medicine to protect your heart.

## How much time will this project take?

I imagine that our interview will take around one hour but could be longer or shorter.

## Will my personal information and participation remain confidential?

If you agree to take part in my project, I will keep all your personal information confidential and make sure it is not shared with any other party. Your interview will only be accessible to me and my PhD supervisors. I will change your name to a participant code, so your views will remain anonymous to anyone reading the published results.

## 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 views and experiences about taking heart medicines. Your participation in this study will hopefully help to improve the ways pharmacists support patients taking heart medicines.

## 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 experiences of taking medicines for your heart, you should mention this to me and we will stop or pause the interview. I will not be able to answer any questions you have about your medicines and your health. If you have any concerns about this we advise you to speak with your own doctor or pharmacist.

## What will happen to the study results?

The study results will be used in my PhD thesis. The outcomes may be presented at conferences and published in research journals. If you would like, a copy of your interview transcript can be given to you. You can also read about the study results when they are published. The anonymous data collected from your interview will be kept securely at the University, and may be used in further studies. With your permission we would like to keep, share and reuse anonymised (this means any information identifying you will be removed) study information after the project ends.

## Do I have to take part?

No. Taking part in this study is voluntary. You don't have to take part if you do not want to. If you do not wish to take part 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 at any time, up until when the results are published.

## What if there is a problem?

If you have any complaints about the way you have been dealt with during the study, please contact either me or my research supervisor – see our contact details at the end of this form.

## 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. We will then arrange a meeting, at a mutually convenient time, to gain your consent and arrange the interview. 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 who are the academic institution for my PhD.

## Who has reviewed the study?

This study has been reviewed and given approval by the University of Reading Research Ethics Committee.

## What are the contact details?

My name is Hannah Piekarz and I can be contacted by email: h.piekarz@pgr.reading.ac.uk
My supervisors are:
Parastou Donyai: p.donyai@reading.ac.uk
Catherine Langran: c.a.langran@reading.ac.uk

## Data Protection

The organisation responsible for protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at imps@reading.ac.uk, or in writing to: Information Management & Policy Services, University of Reading, Whiteknights, P O Box 217, Reading, RG6 6AH.

The University of Reading collects, analyses, uses, shares and retains personal data for the purposes of research in the public interest. Under data protection law we are required to inform you that this use of the personal data we may hold about you is on the lawful basis of being a public task in the public interest. If you withdraw from a research study, which processes your personal data, dependant on the stage of withdrawal, we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your personal data.

If we have included any additional requests for use of your data, for example adding you to a registration list for the purposes of inviting you to take part in future studies, this will be done only with your consent where you have provided it to us and should you wish to be removed from the register at a later date, you should contact Dr Parastou Donyai (p.donyai@reading.ac.uk).

You have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register
- Access your personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details to be removed from systems that we use to process your personal data
- Restrict uses of your data
- Object to uses of your data, for example retention after you have withdrawn from a study

Some restrictions apply to the above rights where data is collected and used for research purposes.

You can find out more about your rights on the website of the Information Commissioners Office (ICO) at https://ico.org.uk

You also have a right to complain the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.

## Consent Form

1. I confirm that I have read and understand the Participant Information Sheet dated 25/11/18 for the above study, which was explained by Hannah Piekarz. 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.

☐

3.I have received a copy of this Consent Form and of the accompanying Participant Information Sheet.

☐

4.I understand that while others may find the discussion interesting and thought-provoking, if I feel uncomfortable in any way during the interview, I have the right to not answer any questions and to end the interview early if I choose.

☐

5. 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.

☐

6. 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.

☐

7. 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.

☐

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…………………………………………………………….

**Name of Participant:**__________________________________________________

Signature: Date:

# Appendix B: Interview Schedules

**Final Version - 30/5/19:**

Interview Schedule

- Go over information sheet verbally, opportunity to answer questions
- Sign consent form and give copy to participant.

Thanks for agreeing to take part today.
The interview is entirely your space to tell me about your experiences of the medicines that you have been given for your heart.
There are no right or wrong answers, and everything that you say is of value to us.
I'm going to ask you a question, and I'd like you have a think, then give me as much detail in your answer as you can.
Take as long as you need and include as much as you can think of in your reply.
If there are any questions that you don't want to answer, or you want to move on, we'll do that.
Any questions? Are you OK to start?

- Turn on recorder

1) We're researching with people who've had a heart attack- How long ago did you have yours?
2) Could you tell me more about what happened?
3) And were you started on your heart medicines in hospital? Do you remember someone talking you through them?
4) Can you describe what it felt like to be given new medicines?
5) Can you tell me the names and a bit about the medicines that you take?
6) Could you tell me your daily medicine routine?
7) Does it fit within your lifestyle?
8) Do you have anything that helps you to take them?
9) Can you think back to a time recently that you didn't take them. Could you describe what happened?
10) What did that experience feel like for you emotionally?
11) Is taking your medicines a high priority for you?
12) What does it mean for you to meet that level of importance?
13) In terms of the internal process you go through, can you describe it?
14) How much do you feel that taking your medicine plays a part in keeping you healthy?
15) What other things are important in terms of keeping healthy?
16) Do you know anyone else in a similar situation as you?
17) Do you see the hospital staff often? Are they useful, and in what way?
18) Is there anyone helpful to you that you see in your surgery?
19) And in the pharmacy?
The next section of questions is about your feelings about the medicine you take. Take all the thinking time you need.
20) What is your view of the medicines that you take for your heart?
21) Is it different from any other medicine that you might take?
22) What does the experience of taking your heart medicine feel like?
23) Does that feeling differ from taking other medicines?
Last couple of questions-
24) How would you describe your relationship with medicines?

25) Do you think that it’s changed since having a heart attack?

Thank you. All done.

I’m going to give you a different name and use that to write up the interview. I can email you over a copy.
I’ll keep in touch, and let you know how the study is going, but it may be a year or two before you hear.

Participants with cause for concern:

> You mentioned that… Perhaps if you talked about this with a pharmacist or someone in the surgery trained to help, I’m sure that there are ways that they can help you to sort out the issues that you’re having.

Or further:

> Let me put you in touch with somebody, which pharmacy do you go to?

**Pilot Version - 21/5/18:**

Talking Hearts and Minds Interview Question Framework
Opening preamble:
Thanks for agreeing to take part today. The interview is entirely your space to tell me about your experiences of the medicines that you have been given for your heart.
There are no right or wrong answers, and everything that you say is of value to us. I'm going to ask you a question, and I'd like you to give me as much detail in your answer as you can. Take as long as you need for thinking time too. If there are any questions that you don't want to answer, or you want to move on, we'll do that.
Start off with a warm up chat about how they found out about the study/ the group/ etc.
IPA Question framework

1. Could you tell me about the medicines that you take to protect your heart?
2. What is your view of these medicines?
3. How does taking them make you feel?
4. How does not taking them make you feel?
5. What does the whole experience of being given medicines to take feel like?
6. What does it feel like being a person who has heart medicines?
7. Do you think of them as different from medicines for other illnesses you may have?
8. Could you describe your outlook on life/ personality?
9. Has this changed since your heart attack?
10. What is it like to be given directions from the medical team?
11. How you feel about taking medicines? And specifically these types of medicines?

Grounded Theory Question framework

12. Could you tell me what medicines you take?
13. Can you describe your daily medicine routine?
14. Does it always go to plan- how does it happen in everyday life?
15. What helps you to take them?
16. What gets in the way of you taking them?
17. What is the experience of taking medicines for your heart like?
18. Can you think of times when you haven't taken them, could you tell me what happened?
19. On these occasions, could you think of reasons why this happened?
20. I'm researching into how people follow their medicine treatments, could you suggest the things that I ought to be thinking about?
21. Could you explain why you feel that each of these things are important?

Non-adherence advice for patients who disclose that their behaviour may be of concern:
You mentioned that… Perhaps if you talked about this with a pharmacist or someone in the surgery trained to help, I'm sure that there are ways that they can help you to sort out the issues that you're having.

# Appendix C: Systematic Literature Review Supplemental Material

**Collated Systematic Search Results 6/7/21**

| Inclusion Criteria |
|---|
| Myocardial infarction patient. |
| Published between 2000 and 2021. |
| Examines patient experience, perspective, requirements of medication taking. |
| Original qualitative data. |
| Available in English. |

### 1) PubMed Search

All fields, no restrictions

| Search | Search Terms | No. of Results | |
|---|---|---|---|
| | | HP 6/7/21 | AR 21/6/21 |
| 1 | "Qualitative research"[MeSH] OR "qualitative research" OR qualitative OR "phenomeno*" OR "experience" OR "content analysis" OR "thematic analysis" OR "grounded theory" OR "ethnography" OR "interview" OR "discourse analysis" OR "conversation analysis" | 1,383,551 | 1,376,309 |
| 2 | "myocardial infarction"[MeSH] OR "myocardial infarction" OR "heart attack" OR "AMI" | 268,812 | 267,960 |
| 3 | "medication adherence"[MeSH] OR "medication adherence" OR "medication compliance" OR "medication concordance" OR "medicine adherence" OR "medicine compliance" | 30,367 | 30,163 |
| 4 | #1 AND #2 AND #3 | 53 | 53 |

South Asians living in the UK and **adherence** to coronary **heart** disease **medication**: a mixed- method study.
Jalal Z, Antoniou S, Taylor D, Paudyal V, Finlay K, Smith F.Int J Clin Pharm. 2019 Feb;41(1):122-130. doi: 10.1007/s11096-018-0760-3. Epub 2018 Dec 18.

Perspectives of Patients and Professionals on Information and Education After **Myocardial Infarction** With Insight for Mixed Reality Implementation: Cross-Sectional Interview Study.
Hilt AD, Mamaqi Kapllani K, Hierck BP, Kemp AC, Albayrak A, Melles M, Schalij MJ, Scherptong RWC.JMIR Hum Factors. 2020 Jun 23;7(2):e17147. doi: 10.2196/17147.

Drug **compliance** after stroke and **myocardial infarction**: a comparative study.
Arif H, Aijaz B, Islam M, Aftab U, Kumar S, Shafqat S.Neurol India. 2007 Apr-Jun;55(2):130-5. doi: 10.4103/0028-3886.32783.

Clinician-patient discord: exploring differences in perspectives for discontinuing clopidogrel.
Garavalia L, Ho PM, Garavalia B, Foody JM, Kruse H, Spertus JA, Decker C.Eur J Cardiovasc Nurs. 2011 Mar;10(1):50-5. doi: 10.1016/j.ejcnurse.2010.04.002. Epub 2010 May 21.

Exploring patients' reasons for discontinuance of **heart** medications.
Garavalia L, Garavalia B, Spertus JA, Decker C.J Cardiovasc Nurs. 2009 Sep-Oct;24(5):371-9. doi: 10.1097/JCN.0b013e3181ae7b2a.

**2) SCOPUS Search**

TITLE-ABS-KEY, no restrictions

| | | No. of Results | |
|---|---|---|---|
| Search | Search Terms | HP 6/7/21 | AR 21/6/21 |
| 5 | "qualitative research" OR qualitative OR "phenomeno*" OR "experience" OR "content analysis" OR "thematic analysis" OR "grounded theory" OR "ethnography" OR "interview" OR "discourse analysis" OR "conversation analysis" | 4,913,231 | 4,884,827 |
| 6 | "myocardial infarction" OR "heart attack" OR "AMI" | 306,578 | 305,752 |
| 7 | "medication adherence" OR "medication compliance" OR "medication concordance" OR "medicine adherence" OR "medicine compliance" | 45,422 | 45,123 |
| 8 | #5 AND #6 AND #7 | 106 | 105 |

Perspectives of patients and professionals on information and education after myocardial infarction with insight for mixed reality implementation: Cross-sectional interview study
Hilt, A.D., Kapllani, K.M., Hierck, B.P., (...), Schalij, M.J., Scherptong, R.W.C. 2020 JMIR Human Factors 7(2),e17147

South Asians living in the UK and adherence to coronary heart disease medication: a mixed-method study
Jalal, Z., Antoniou, S., Taylor, D., (...), Finlay, K., Smith, F. 2019 International Journal of Clinical Pharmacy 41(1), pp. 122-130

Identifying determinants of medication adherence following myocardial infarction using the Theoretical Domains Framework and the Health Action Process Approach
Presseau, J., Schwalm, J.D., Grimshaw, J.M., (...), Sullivan, K., Ivers, N.M. 2017 Psychology and Health 32(10), pp. 1176-1194

Clinician-patient discord: Exploring differences in perspectives for discontinuing clopidogrel
Garavalia, L., Ho, P.M., Garavalia, B., (...), Spertus, J.A., Decker, C. 2011 European Journal of Cardiovascular Nursing 10(1), pp. 50-55

Impact of community pharmacist intervention discussing patients' beliefs to improve medication adherence
Gujral, G., Winckel, K., Nissen, L.M., Cottrell, W.N. 2014 International Journal of Clinical Pharmacy 36(5), pp. 1048-1058

Exploring patients' reasons for discontinuance of heart medications
Garavalia, L., Garavalia, B., Spertus, J.A., Decker, C. 2009 Journal of Cardiovascular Nursing 24(5), pp. 371-379

Drug compliance after stroke and myocardial infarction: A comparative study
Arif, H., Aijaz, B., Islam, M., (...), Kumar, S., Shafqat, S. 2007 Neurology India 55(2), pp. 130-135

**3) PsycInfo**

Keywords, no restrictions

| Search | Search Terms | No. of Results | |
|---|---|---|---|
| | | HP 6/7/21 | AR 21/6/21 |
| 9 | "qualitative research" OR qualitative OR "phenomeno*" OR "experience" OR "content analysis" OR "thematic | 856,671 | 853,278 |

| | | | |
|---|---|---|---|
| | analysis" OR "grounded theory" OR "ethnography" OR "interview" OR "discourse analysis" OR "conversation analysis" | | |
| 10 | "myocardial infarction" OR "heart attack" OR "AMI" | 6,221 | 6,209 |
| 11 | "medication adherence" OR "medication compliance" OR "medication concordance" OR "medicine adherence" OR "medicine compliance" | 7,829 | 7,803 |
| 12 | #9 AND #10 AND #11 | 13 | 12 |

Impact of community pharmacist intervention discussing patients' beliefs to improve medication adherence
G Gujral, K Winckel, LM Nissen, WN Cottrell
International journal of clinical pharmacy, 2014, 36(5), 1048-1058 | added to CENTRAL: 31 December 2014 | 2014 Issue 12

South Asians living in the UK and adherence to coronary heart disease medication: a mixed-method study
Z Jalal, S Antoniou, D Taylor, V Paudyal, K Finlay, F Smith
International journal of clinical pharmacy, 2019, 41(1), 122-130 | added to CENTRAL: 31 March 2019 | 2019 Issue 3

### 4) Cochrane Library

TITLE-ABS-KEY, no restrictions

| | | No. of Results | |
|---|---|---|---|
| Search | Search Terms | HP 6/7/21 | AR 21/6/21 |
| 13 | "qualitative research" OR qualitative OR "phenomeno*" OR "experience" OR "content analysis" OR "thematic analysis" OR "grounded theory" OR "ethnography" OR "interview" OR "discourse analysis" OR "conversation analysis" | 88995 | 156830 |
| 14 | "myocardial infarction" OR "heart attack" OR "AMI" | 33706 | 33208 |
| 15 | "medication adherence" OR "medication compliance" OR "medication concordance" OR "medicine adherence" OR "medicine compliance" | 8767 | 8649 |
| 16 | #13 AND #14 AND #15 | 59 | 50 |

Impact of community pharmacist intervention discussing patients' beliefs to improve medication adherence
G Gujral, K Winckel, LM Nissen, WN Cottrell
International journal of clinical pharmacy, 2014, 36(5), 1048-1058 | added to CENTRAL: 31 December 2014 | 2014 Issue 12

South Asians living in the UK and adherence to coronary heart disease medication: a mixed-method study
Z Jalal, S Antoniou, D Taylor, V Paudyal, K Finlay, F Smith
International journal of clinical pharmacy, 2019, 41(1), 122-130 | added to CENTRAL: 31 March 2019 | 2019 Issue 3

### 5) Web Of Science

All databases, keywords, no restrictions

| | | No. of Results | | |
|---|---|---|---|---|

| Search | Search Terms | HP 6/7/21 | AR 21/6/21 | HP 5/8/21 |
|---|---|---|---|---|
| 17 | "qualitative research" OR qualitative OR "phenomeno*" OR "experience" OR "content analysis" OR "thematic analysis" OR "grounded theory" OR "ethnography" OR "interview" OR "discourse analysis" OR "conversation analysis" | 4,541,098 | 206,505 | 4,586,701 |
| 18 | "myocardial infarction" OR "heart attack" OR "AMI" | 528,393 | 55,436 | 530,271 |
| 19 | "medication adherence" OR "medication compliance" OR "medication concordance" OR "medicine adherence" OR "medicine compliance" | 39,932 | 5,177 | 40,275 |
| 20 | #17 AND #18 AND #19 | 137 | 1 | 138 |

Core collection

| Search | Search Terms | HP 5/8/21 |
|---|---|---|
| 17 | "qualitative research" OR qualitative OR "phenomeno*" OR "experience" OR "content analysis" OR "thematic analysis" OR "grounded theory" OR "ethnography" OR "interview" OR "discourse analysis" OR "conversation analysis" | 2,683,000 |
| 18 | "myocardial infarction" OR "heart attack" OR "AMI" | 325,065 |
| 19 | "medication adherence" OR "medication compliance" OR "medication concordance" OR "medicine adherence" OR "medicine compliance" | 21,353 |
| 20 | #17 AND #18 AND #19 | 85 |

(All databases) HP's results:

Perspectives of Patients and Professionals on Information and Education After Myocardial Infarction With Insight for Mixed Reality Implementation: Cross-Sectional Interview Study.
By: Hilt, Alexander D; Mamaqi Kapllani, Kevin; Hierck, Beerend P; et al.
JMIR human factors Volume: 7 Issue: 2 Pages: e17147 Published: 2020 Jun 23

"It's up to me with a little support" - Adherence after myocardial infarction: A qualitative study
By: Hanna, Admi; Yael, Eilon-Moshe; Hadassa, Levy; et al.
INTERNATIONAL JOURNAL OF NURSING STUDIES Volume: 101 Article Number: 103416 Published: JAN 2020

South Asians living in the UK and adherence to coronary heart disease medication: a mixed-method study
By: Jalal, Zahraa; Antoniou, Sotiris; Taylor, David; et al.
INTERNATIONAL JOURNAL OF CLINICAL PHARMACY Volume: 41 Issue: 1 Pages: 122-130 Published: FEB 2019

Clinician-patient discord: Exploring differences in perspectives for discontinuing clopidogrel
By: Garavalia, Linda; Ho, P. Michael; Garavalia, Brian; et al.
EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING Volume: 10 Issue: 1 Pages: 50-55 Published: MAR 2011

Exploring Patients' Reasons for Discontinuance of Heart Medications
By: Garavalia, Linda; Garavalia, Brian; Spertus, John A.; et al.
JOURNAL OF CARDIOVASCULAR NURSING Volume: 24 Issue: 5 Pages: 371-379 Published: SEP-OCT 2009

Drug compliance after stroke and myocardial infarction: A comparative study
By: Arif, Hiba; Aijaz, Bilal; Islam, Muhammad; et al.
NEUROLOGY INDIA Volume: 55 Issue: 2 Pages: 130-135 Published: APR-JUN 2007

# Appendix D: Narrative Analysis Supplemental Material

Narrative Full Table by Arc Group

**Beki B**

| Stage | Quote | Notes |
|---|---|---|
| **Returning Home – ‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | He then put me on, on statin. Atorvastatin. Um-<br>. And reduced my beta-blockers. Which was good cause taking a beta-blocker is like wading through treacle. | Medic acting to decide medication. |
|  | This is my discharge from cardiac rehab,<br>but I think my discharge from um, hospital, um.<br>After I'd had the stents (sound of paper rustling)<br>Said in bold letters ‘If you do not take this every day you will die.’<br>OK.<br>Because of the risk of clots, / Uh-huh./ um-<br>So that was quite- and it’s in, in capital letters, so that was quite<br>‘OK, I'll take it.’<br>But I also know that whilst it’s indicated for twelve months,<br>Actually you’d probably only need to take it for six. So-<br>I kind of know. So I'd had to stop taking it for five days<br>Um- (Tsk) before I could have the operation on this, because of the risk of blood loss/ Yeah.<br>Erm, so er- but I wasn’t, but they then asked the cardiologist<br>Whether I would need cover by not taking it<br>But because I'm nine months post-event | Summary exaggeration- You will die – shock<br>Strong persuasion. |

| | | |
|---|---|---|
| | and I guess a lower risk of clots than probably other people,<br>I wouldn't need to have anything else. So.<br>So, yeah. It was a - Yeah. | |
| | And obviously when you come off a beta blocker you take it slowly<br>So I think I you know, half them and then half again, whatever.<br>So, by six months post heart attack, I'd come off the beta blocker.<br>Then - a year- (Huh) following... So, sorry, go back slightly. | Second person. You – Come off.<br>First person. I'd – come off |
| | Errh. I have an alarm set on my phone, for the evening.<br>OK.<br>Um. I don't always take it as soon as the alarm goes off, but it's more of a trigger to go 'yes, you must remember to take those before you go to bed.'<br>Cause they're all just down in the kitchen because the Ticagrel is morning and evening<br>I can't have them up in my bedroom, because<br>then morning ones, if you see what I mean,<br>the aspirin has to go in water / OK. / and so<br>I just, um, whilst I appreciate polypharmacy-<br>Not necessarily ideal, I literally, just - I mean the aspirin's in the water/ uh-huh.<br>But the others I just literally take all three, in my mouth at once and just.<br>But I also have no issue with swallowing tablets | Timing prompt<br>Location prompt |
| | | |

| | | |
|---|---|---|
| **Crisis Point – 'Man Overboard!'**<br>'Existential Crisis'<br>Regressive to Progressive and then some | yes I'm on a statin, but I think my cholesterol on leaving hospital was (refers to letter) Two point three. Erm. So. It's not -<br>If anything /Uh-huh. / I'm slightly concerned that my cholesterol will get-<br>And this was before I started taking the highest dose of atorvastatin.<br>If anything I'm slightly concerned as to whether my cholesterol will go too low but I don't know<br>I haven't really<br>When I go back to the GP, erm in October<br>To review my medication, I will ask them about that.<br>Cos I have to, have to have my lipids done<br>Every year, so, we'll see. / OK. / | A worry that meds work too well – taking too much.<br>Will ask medical team for change. |
| | A year later- March- ish time... I was...<br>He referred me to the silver star service at [City] at the [Hospital]<br>Which is the high-risk maternity unit<br>So it's for people that have got, either high-risk-<br>the mothers are high-risk /Mm. /due to some-<br>Or the pregnancies are high-risk<br>Due to either the health of the child. Or a combination of, of both. / Right.<br>So I was referred there (Huh) and they have a cardiac clinic- once a week- ahmm-<br>And even, I wasn't pregnant at that time- but to discuss Medication and things | Becoming pregnant is a high priority, and high risk. |
| **Balancing Pros and Cons**<br>**'Nobody wants to rock the boat'**<br>'Fits and Starts' | At that point I came off the pill and then came off | I came off- personal action<br>She's responsible for this |

| | | |
|---|---|---|
| Regressive to Progressive back and forth | The statin- and the clopidogrel, and just stayed on<br>Aspirin. / Yeah. / and they agreed – we could try -<br>So, my – I guess by about August, my year, which was 2015<br>I was pregnant. | Team agreement. |
| | Then I... breast-fed him for about six or seven months<br>So come (Hu). November December time I went back on the statin<br>And. Clopidogrel. | Passive verb ‘went back’ |
| | My poor husband, sort of two or three weeks after I'd come out of hospital, one nightI mean amazing for sleeping, oh my god,<br>you’d sleep amazingly on a beta blocker-<br>But umm- he woke up and my hands were freezing cold, and he’d thought I was dead.<br>(Laugh)<br>(Laugh)<br>Cause my breathing was so shallow,<br>Yeah.<br>And then woke me and I was grumpy and like, why the Hell did you wake me up?<br>But he kind of, so he wasn’t massively keen | Side effects impact on husband - Being viewed by husband<br>Told what’s happened? |
| | I went back to my private cardiologist / Ok. Yep. / after I'd been discharged from the [Hospital]<br>And he doubled my dose of statin<br>Cause he said ‘What the heck- Er. If you can tolerate it. Then- you should take it.’<br>I would add my cholesterol is non-existent.<br>And I’ve never had high cholesterol. /Hhh. Yep/<br>It’s more for the um, artery, the arterial benefits/ Ok. Yep. | Medic active decision.Vivid character dialogue<br>Subtext – she's in good health |

| | | |
|---|---|---|
| | / than anything else that I take it.<br>And he said that maybe my cholesterol was just high for me<br>If you see what I mean, that everybody has their set point, / yeah. / and mine was just very low.<br>But I have no family history of any cholesterol – issues. | |
| | And I now, although when I first was prescribed them I didn't take my statin in the evening, as well<br>Because I think, I don't think I was actually ever told<br>And I probably didn't read the leaflet<br>Er- And I know that actually atorvastatin is longer acting so<br>It's less of an issue, so / Mm. /<br>I take those two in the evening.<br>So, yeah. I mean it's part of the routine- | Passive action 'was prescribed'<br>Mitigation of her error<br>Considers it's not that important |
| | Er. I think, probably I was out. And then thought, oh yeah, I must take this when I get home<br>Or, um, and just didn't 'cause I came home and went straight up to bed for example, / Yeah.<br>Or, er, I think I've missed three ticagrel in a year<br>Well ten months, eleven months, whatever. So. / Yeah.<br>Apart from when I had this operation, I had to stop taking it<br>For five days. | Very rarely misses medication now<br>Idea of scale<br>An example of when stopped on purpose |
| | The only side effect I have from the drugs is<br>The ticagrel and the bruising is horrendous.<br>Like really horrendous, | Almost intolerable side effect |

| | | |
|---|---|---|
| | I look like a battered wife, most of the time<br>Less - at the moment because I'm not really doing anything physically.<br>But this, this is one. I walked into a post<br>And actually, it’s almost gone now,<br>But it was huge.<br>And anything.<br>I’m actually very good at the moment,<br>But I had a bruise there,<br>Just generally covered in bruises<br>Permanently from the, from the medication<br>Cause when I stopped it for five days,<br>I noticed that I'd<br>Didn’t bruise nearly as often, so<br>That's. Um - It's a side effect which I knew,<br>Which I was aware of, but, you know<br>It’s just one of those things, you just have to<br>For the sake of a year.<br>If I was taking it for the rest of my life,<br>I would - maybe have a discussion with a doctor,<br>But for the sake of a year, it, it’s fine. Um. | How it makes her husband look?<br>It is getting better<br>It was worse than this<br>Personal experimentation<br>Knowledge of this from before<br>Limited time scale<br>Split decision, ask medical team<br>The timescale makes it tolerable |
| **<u>Continued Living – reaching ‘Plain Sailing’</u>**<br>‘Slow Climb ’<br>From Progressive to Stable | When it doesn’t change the medication you’re on.<br>Um, so, I kind of, yes. So, I take my drugs every day<br>But I try and just, just do it,<br>I don’t.  try not to dwell or think<br>Why has that or when’s it going to happen<br>Otherwise I'd never get anything - done.<br>Uh-huh. | No power to amend medication.<br>Just try and carry on. |

| | | |
|---|---|---|
| | It’s just part of, you know, I come down in the morning Get my breakfast, I eat it, I take my tablets.<br>It’s just so- Yeah. I mean it's something that I remember to do every day | Example of the everyday<br>Just – the accepted normal<br>Just |

**Carl B**

| Stage | Quote | Notes |
|---|---|---|
| **Returning Home – ‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | Right, so this is a photograph taken with my mobile of the yellow card. That everyone gets given. And so that's the tablets and the dosages, which doubtless you'll be interested in, and then next to it, the pharmacist has written why I'm taking it. And then then they tell you when to take it, and then for some reason to put you off.<br>They tell you about the side effects in the third column from the end. | Given a card. Directive. Impersonal introduction to meds.<br>Second person ‘they’ other, impersonal<br>Try to discourage patients<br>Side effects info as negative |
| | The tablets that the cardiologist put you. On is that at. At that time they were treating everyone quote - aggressively -with atorvastatin 80mg the standard dose that they give to people is 10 mg. | Cardiologist takes action<br>You – object<br>Aggressive, defensive battle talk |
| | Being told you've had a heart attack and you've got to take all these tablets for the rest of your life. I I didn't take it particularly well, but what could you do? Yeah, yeah, they obviously knew what what they were doing.<br>Or so I thought at the time. Well, you're under the the care of a cardiac surgeon. | A shock to take in.<br>Difficult, but powerless<br>Medics have power<br>In hindsight – has since changed opinion of medics<br>Under surgeon’s care<br>Unaware, passive |

| | | |
|---|---|---|
| | 'cause when I went into hospital I was unaware I had a heart attack. | |
| **Crisis Point – ‘Man Overboard!’**<br>‘Existential Crisis’<br>Regressive to Progressive and then some | Because I react very easily to these things, half of a Paracetamol will have me lapse into. unconsciousness, so 80 mg of atorvastatin resulted in me feeling like I Was having malaria every night. So I complained to the cardiac nurse and she rolled her eyes to heaven and reduced it to 40 immediately. But later the GP reduced it to 20. | Background, he’s sensitive to drugs<br>Exaggeration?<br>Experiencing side effect<br>Action- complained to nurse<br>Unsympathetic<br>Result- dose reduction<br>Validated further at later date by GP |
| | And then ramipril. We run into trouble because it goes for your throat. You see, the pharmacist has noticed as a side effect of dry cough.Well, that's an understatement. It sort of strangles your voice, so they took me off that and. Put me on um. Candesartan | New story.<br>Background info –<br>goes for your throat, like a vampire?<br>Underplaying<br>Medics acted change |
| | And then then, of course, it begs the question, why do you need the- The the medication because almost all the the medicines that you're getting are duplicated by the foods you're eating. You know they lower cholesterol. They lower blood pressure. They give you blood thinner and so on. So I I got to the stage by 2019 where I advised the doctor. I was taking myself off all the tablets. And I wrote him a letter, and we he summoned me in. We had a chat and he agreed.<br>OK.<br>Well, you probably would if you've only got 10 minutes | Framing the next story<br>Reached crisis stage<br>He told GP his plan<br>Put into writing,<br>Discussed in person, GP OK’d it<br>(the sound of researcher’s jaw drop)<br>He considers that he’d put the GP into a bind. |

| | | |
|---|---|---|
| | and the patient turns up with a one page, An A4 letter. | |
| | Ticagrelor an antiplatelet, blood thinner. This was an absolute nightmare 'cause it caused my veins to swell look like something in a horror film And so my GP took me off it. And then he got a very sharp note from the hospital to put me on to clopidogrel instead, which was what went they'd been using before. | Nightmare – worst imagining<br>Horror film analogy again<br>GP made choice to stop meds<br>Hospital have superior jurisdiction |
| **<u>Balancing Pros and Cons</u>**<br>**<u>‘Nobody wants to rock the boat’</u>**<br>‘Fits and Starts’<br>Regressive to Progressive back and forth | And then leave you and the GP to argue over the next few years. Something more tailored to your own requirements. Cause in Hospital haven't got time to sit down with you and work out what might or. May not. Suit you and what have you that that that's got to be done with the aftercare. | A discussion with GP to tailor medciation, no time to do this in hospital |
| | Well, 'cause you have to watch the GPs when they're renewing the prescriptions 'cause they don't. I mean I had six GPs in seven years. They don't really have that many heart patients and they don't know really what they're doing. In many cases, only one GP, in my view, had had any idea of. What it was all about. | Internal suspicion of GPs.<br>Busy, lack care – Impersonal<br>They are not specialists or have experience with AMI |
| | he said, well, you should stick on the aspirin. And had a very strong case for. Doing that. Despite the fact that, uh, I'm I'm 76. I'm 77 tomorrow and um. | GP convinces him to remain taking aspirin with balanced argument.<br>His counterargument is his age, implication – what extra life will it afford him? |
| | ‘What's happening,’ she said. ‘The advice has changed.’<br>I've got to work out how to come off them and well. | A reversal – he's been told to stop aspirin.<br>And plans to follow this direction... |

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| | I'm a bit reluctant to come off them at the moment because they're they're indicated as you probably know, for a um. Defence against COVID where it's alleged they give you a 50% protection against blood clots. | Eventually. Balancing risk against perceived benefit. |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | Well, you just put them into your meal routine. OK. 'cause it tells you when. To take them, yeah. | Just – normal<br>Routine, regular, no effort<br>Following directions |
| | Yeah, yeah, I've just had the latest one. In fact since I came off the tablets, my cholesterol has gone up slightly. Now it's now average. But interestingly after the cardiac nurse said that the doctor had queried whether I should go back on statins. And she didn't even suggest it. | Evidencing he's extra healthy.<br>Nurse omits GP suggestion. |

**Chris A**

| Stage | Quote | Notes |
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| **Returning Home – 'Anchors Away'**<br>'Out of the Gate'<br>Regressive to Progressive gradually over time | A pharmacist came up and um,<br>Sort of took all the pills I came in with, and then um, came back a day or so before I left, with all my new ones. | Still in hospital – dominance of staff |
| | It's just damaging the planet<br>And they- the government should be- it's also<br>Costing the NHS probably more money<br>For the packaging than the pills I'm taking<br>Uh-huh.<br>And that's an absolute disgrace.<br>Yeah.<br>So I, I just get rid of that stuff as soon as I possibly can because | Personal affront to environmetal damage |

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| | I'm just - I'm appalled, /<br>Mmm.<br>At the wastage, of the wastage,<br>And the damage being done to the planet<br>And the money that's being spent by the NHS<br>That could be being spent on patient care. | |
| **Balancing Pros and Cons**<br>**'Nobody wants to rock the boat'**<br>'Fits and Starts'<br>Regressive to Progressive back and forth | If I – if I had. I haven't got any side effects<br>Other than the weight gain for this other one for the back.<br>So- um- er, no. I think, um, I-<br>I just sort of take it sensibly<br>And if I didn't think I needed it<br>I wouldn't- I would seriously think of, um reducing them,<br>But most of these, my bisoprolol and that sort of thing, / Mm.<br>I'm on about as low as you can go anyway<br>I don't think bisoprolol comes lower than two point five milligrams.<br>Uh-huh.<br>So anyway, don't stop that,<br>'cause I don't think would be a good idea,<br>'cause it helps with the heart rate.<br>Uh-huh.<br>I'll stick with that one<br>I wouldn't stop that one.<br>Without taking advice. | If ...then<br>Had side effects, then would ask medic |
| | It's just there, and it just works. Yeah. Fine.<br>And I guess it helps. I wouldn't like to experiment<br>Like I do with the gabapentin or ropinirole<br>Wouldn't want to experiment with the enalapril or the amlodipine.<br>Um, to see whether I - my heart felt better or worse. | Existential – won't mess with this group of medication. Cardiac treatment is more important than back pain or restless leg syndrome. |

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| | That's- you know, if that's what the doctors say then I'll<br>Just get on with it<br>And 'til they say something different, um<br>I won't, I won't question it. | Medical directives must be followed, until they say so. |
| | At one point I was on two point five milligrammes of bisoprolol<br>In the morning and in the evening and<br>They said I didn't need them quite so much so<br>They said drop one, and I dropped the evening one.<br>OK. And /But I'm very much in the sort of<br>take them when it fits me. | Minor change, adapts to suit his life. |
| | I think when I'm halfway through taking the morning lot and something happens, you know<br>Mmm.<br>Or something distracted me totally,<br>I might then look at the box and say<br>How far did I get?<br>Yeah.<br>But, um, if I, if I repeated the last four on a, on a given morning, or<br>Forgot them, um, or forgot the whole lot<br>It doesn't actually affect me<br>None of them are things that are life-threatening if I miss a day or take too many<br>Uh-huh. Yeah.<br>That's the sort of er-<br>Once you know that, you're just um, totally relaxed. | Memory process omission, not worried about it. |
| **Crisis Point – 'Man Overboard!'**<br>'Existential Crisis'<br>Regressive to Progressive and then some | | |

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| **Continued Living – reaching ‘Plain Sailing’**<br>‘Slow Climb ’<br>From Progressive to Stable | I just- one of the ones<br>I just throw in the morning ‘cause it’s more convenient to me<br>My readings seem to come out OK. | Slapdash process, biometric result not affected |
| | But I’m very much in the sort of<br>take them when it fits me.<br>Yeah.<br>And that goes for the pills for the cardiac, the legs and the stenosis in the back.<br>Uh-huh.<br>So you don’t see them as different from any other medicines that you take, it’s just-<br>Yeah, they’re just, they’re just pills. | Adapts med to life |
| | I have no emotions at all<br>I just sort of um, pick them up, chuck them in and swallow them.<br>Uh-huh. Yep.<br>Um, there are time when I think,<br>‘oh, not these again’ but to look at them<br>Looking at them now with them sitting in front of me,<br>Um, well, you know, they’re there,<br>And maybe I'm here because they’re there | Unemotional, but reflects that meds may be keeping him alive. |
| | Whereas I feel very loathe<br>To take, to take any other pills of that sort<br>I would really have to, struggle with those<br>And if I'm put on antibiotics as has obviously in the last nine years<br>Mmm.<br>It’s, it’s, I kind of resent those. | Cardiac meds are different; takes them as part of life. |

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| | But I kind of get on with all of the others as part of normal life. | |
| | But I just take them, because they're there and<br>Because, um, they're recommended in my situation.<br>And whenever, you know, every three or four years<br>I sit down with the GP and she and I have a chat about it and,<br>As long as I'm happy, and she's happy<br>Then we carry on with- whatever we're doing. Yah.<br>M-huh. | All parties are satisfied, carry on. |

**Colin B**

| Stage | Quote | Notes |
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| **Returning Home – 'Anchors Away'**<br>'Out of the Gate'<br>Regressive to Progressive gradually over time | But it was all, so um, new then, that it was - I wasn't<br>In the best for a couple of days<br>Uhm, so it was a little bit difficult to know exactly what each one was meant to be doing.<br>OK.<br>But the fact that I was going to be referred home<br>Um and they said I'd be fine until I got home<br>-And that um, I suppose eh, I was satisfied with that. | Disorientated following admission. |
| | And I have to say I've had<br>Hardly any, hardly any, or probably never<br>After the first six months<br>/Uh-h. | All discussion has been with consultant. |

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| | Had any discussion with the GP about this.<br>OK.<br>(---) Has been with this consultant. Uh. | |
| **<u>Balancing Pros and Cons</u>**<br>**<u>'Nobody wants to rock the boat'</u>**<br>'Fits and Starts'<br>Regressive to Progressive back and forth | But they made it clear, from the outset,<br>That um, I just have to take these forever.<br>OK.<br>-at some strength or other<br>Erm, so I just got on with it. | Lifelong medication, accept and continue with taking. |
| | And if we're going out<br>And I know, obviously that wouldn't apply<br>Then I do take the medicine out from the sort of medicine pouch<br>And leave them out, just to remind me. Ok.<br>But generally, I don't. I don't miss anything. | Makes adjustments to remember |
| | No, erm, the only quite, um, difficulty, I suppose.<br>Is, er, if we go out for a meal, or with friends, and that sort of thing. Mmm.<br>Sometimes, because, the, evening<br>The ramipril and statins that I take in the evening, um,<br>I think I've been told it doesn't matter what time,<br>But take them just before you go to bed. / Yeah.<br>But the aspirin should obviously, be just after a meal. Yeah.<br>So, although taking omeprazole, whether that matters,<br>um, you might know more than me.<br>So, um. Aspirin, I want to take, if I'm in a restaurant<br>S'll just take an aspirin out<br>Otherwise take it when I get home. | Change of routine requires extra work to remember |

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| | If it’s a long time before I get home and I haven’t taken it<br>Then I'll take it in the following morning. Uh-huh. | |
| | I think- I hope, the medication that I take,<br>Isn't just dependent on- that, for the next day.<br>I’ve been taking them for such a long time<br>Some of that medication- a level of that medication<br>Has built up, /M-huh.<br>With me, and therefore<br>If one of the is a little but late, / Mmm.<br>If I don’t remember,<br>Or if I do omit one, then<br>I er, I’m always an optimist,<br>Then I think that shouldn’t be a problem. | Long term preventative-small omission won’t matter |
| | I don’t get worried if I, if i don’t take them. Mm-huh.<br>Er-m, er-m. Because, if it, well.<br>I don’t get worried, but if I um, if I noticed,<br>If I felt anything, if I felt differently, / Yep.<br>Then, erm, I might make some enquiries. Mmm. | Unnoticed effect, but if noticable, might seek help |
| | I mean sometimes I think, well,<br>What would happen if I stopped taking all of them?<br>And, um. Who knows? Ha-h. /Mmm.<br>I don’t know whether they’re keeping me fit or<br>Whether<br>I guess they’re/ Hhh. / I don’t know<br>But I'm not bothered enough<br>To want to try, really / That’s right.<br>If its- if it’s working, carry on. | Questions if they’re working, but happy to continue with them |

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| | And really, not too much happened after that.<br>Er- Apart from some changes to the strength of the medication<br>And er, after a while the clopidogrel was dropped.<br>But I think that I was on clopidogrel probably longer than, er<br>Most people would recommend. | Dose amaendments, stopped clopidogrel, taking for longer than other patients. |
| | I was on the same medication that we just mentioned. Yeah. Erm- all the same- yeah, and then as a say, erm,<br>He wanted me to continue on clopidogrel for another year from there,<br>And – the suggestion of reducing the bisoprolol to one point two five<br>I don't think that happened at the time. | Minor adjustments to medication as consultant's recommendation |
| | And the other thing is. They er- at sometime,<br>After about five years on the Omacor<br>They stopped paying for the Omacor. It was do it yourself, if you want to.<br>So I do. Ok. Hm. | Insurance stopped providing Omacor, so covers cost personally. |
| | Really, um, only think about it when I'm going to see the consultant.<br>I'll say, 'is it OK that I'm still on this medication?'<br>Um, do you still- should I still be taking Omacor? / Uh-huh.<br>And even though the reports say it's rubbish<br>He, he reckons that it's very worthwhile. Ok. Hm.<br>So it's - huh- I keep saying to him,<br>You know it's costing me twenty-five pounds a month all this. / H-hhh. | Takes consultant advice about fish oils, but skips dose if obtaining through diet; cost saving! |

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| | Uh- he says, ‘O-eh, yeah’ and just get on with it. /H-hh.<br>Um, the other thing is, I suppose um,<br>I don’t take one if I've say eaten<br>Either salmon or- mackerel.<br>Yeah.<br>And that’s because?<br>Oily fish, in the same way that these tablets are.<br>And that’s because you don’t want to overdo it, or is it just to save a-?<br>Ah- save a pound! / Ha-hhh.<br>Ha. No not really. It's just<br>When I say at the consultant should I take these?<br>He says unless you have three or four doses of oily fish a week<br>You’re better off taking them.<br>OK. Ya.<br>So- er, so I take them. | |
| | Yeah, I’ve read the leaflets about what they do<br>And what the side effects are, that sort of thing, /Mm.<br>And if I had any of those, th’yeah<br>I think we’d discuss it.<br>But my only question , I think, to the consultant<br>When I see him is ‘Does this continue to be, the right medicine<br>the right medication?’ | Keeps informed and aware of issues. Looks to medic for confirmation . |
| **Crisis Point – ‘Man Overboard!’**<br>‘Existential Crisis’<br>Regressive to Progressive and then some | The might be the tre- so two years after the cardiac arrest<br>Uhm, and had, um bleeding.<br>OK. And, that on review, said to be gastric irritation.<br>Uhm- that was almost certainly attributable to the aspirin.<br>Right, OK.<br>Now, the result of that was that the aspirin that the consultant who did all that. | Was “um, bleeding” - not significant to him?<br>Consultant makes change to meds. |

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| | He recommended that I switched the aspirin that I was taking which was just the bog standard / Mm.<br>To, uh- wha' d'ya call tha- enteric coated.<br>Yeah. Yeah.<br>And I've been on that ever since. | |
| | Um, and then the statin was reduced to twenty<br>After about three years, /uh-huh<br>And the omeprazole reduced to twenty<br>Sorry, after the stomach erosion- started taking omeprazole<br>Yes. OK. / to counter the aspirin.<br>Started on forty and then reduced to twenty / Uh-huh.<br>And the statins were reduced to twenty. K.<br>And I've been carrying on like that ever since. | Minor dose changes, omeprazole to counter aspirin effect |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | I mean the only thing erm, is being discussed<br>Is what's best to take in the morning,<br>What's best to take in the evening. Yeah, yeah.<br>So uh- but the way that I've been taking them at the moment<br>Has been settled for quite a long time.<br>And there's only- there's still a little bit<br>Of a discussion, 'well, you could take your ramipril in the morning<br>Instead of in the evening.'<br>But I think on balance they still think it's better to be taking in the evening. Uh-huh.<br>But having said that, having said that, I erm- | The review discusses timings.<br>Not experiencing side effects |

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| | What can I say? I – they don't seem-<br>I don't notice that I've taken anything.<br>Let's put it that way. OK.<br>I don't have any side effects at all<br>As far as I know. Yeah. | |
| | Because after every exercise test, then the consultant writes to the GP / yeah<br>And recommends continuation of the medication<br>And nobody, I don't think anybody knows me<br>Or my situation even<br>To er, I don't think they've got time<br>To look at it and think | GP recommends continuation – worry that he's overlooked. |

**Gaye A**

| Stage | Quote | Notes |
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| **Returning Home – 'Anchors Away'**<br>'Out of the Gate'<br>Regressive to Progressive gradually over time | Because I've never taken medication - other than – other than something for a headache. Something like that. And – um –<br>I didn't have any surgery – so - I think the medication was something - | Going from taking nothing to 'rattling'. |

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| | I was told that every – everybody who has a heart attack has to go on.<br>I think almost irrespective of what else has been done, like stents or bypass or whatever, you know.<br>That – that's the way it was explained to me.<br>So I knew that I had to have this – this raft of medications and um - sort of –<br>M-huh.<br>feel that I would sort of rattle if somebody shook me (Laugh)<br>I was taking so many things. | |
| **Balancing Pros and Cons** **‘Nobody wants to rock the boat’**‘Fits and Starts’ Regressive to Progressive back and forth | Yes, I’ve forgotten. There are times that I’ve forgotten them - it's been a particularly busy day and it’s not until the evening that I've thought, ‘oh, crikey, I've forgotten that ‘.<br>M-huh.<br>Because of my grapes, (Laugh) | Missed doses, exclamation of surprise. |
| | I suppose it is, but it’s just because such a pro – such a routine.M-huh.<br>I would, I would – love – not to have to take them, and I’ve asked my GP – endless times -<br>Um - and he’s just said no. You have to keep on taking them.<br>Yeah. And what does it mean to you to – um - continue taking your medicines?<br>Erm – well – I suppose - I’m here. (Chuckle) And I’m pleased that I'm here, so if it helps me to continue being here, then it’s worthwhile. | Wants to not take them, but accepts that continuation of medication is necessary. |
| | (Sigh) As I say, I really wish that I didn’t have to take them. Mm. | Has unanswered questions, but dominance of medical system implies continuation of medication. |

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| | It's not an imposition - It's just ah – are they doing what they're supposed to do?<br>Um – And what would happen if I didn't take them? Really.<br>Erm – And is that view different from any other medicine that you might have to take?<br>No, I think it's – I think it's - yeah. As I said earlier. I think that if the dosage had been explained<br>Or the dosage could be explained, I think that would make a difference, perhaps.<br>I think that my – am I on the highest? Am I on the lowest? Am I in the middle? Um – am I - I suppose<br>The combination, how does the combination work? Together? That, that sort of information, really.<br>Yeah. OK. And um – having to take medicines for your heart, what does that experience feel like?<br>. It's just – obviously, I'm being told it's a necessity/ Mm / as opposed to me deciding / M / deciding I'd (laughs) like to take these (wheeze) | |
| **Crisis Point – 'Man Overboard!'**<br>'Existential Crisis'<br>Regressive to Progressive and then some | I have a medication review every – every year. Mm.<br>Well – That's the extent of the monitoring that I have.<br>Ok.<br>I did ask if I could see a cardiologist<br>Just to – um – review medication – and what else it might be.<br>And I was told no - you could only see a cardiologist if you have a problem. | Concerned that cardiologist isn't monitoring her, but dismissed by medical system. |

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| | If you don't have a problem, they won't see you. Uh-m.<br>So - um - /Everything goes through your GP and that's the - top of the -<br>Yeah - the GP or the pharmacist. | |
| | And I did take the statin in the morning as well.<br>I found the I was having – uh - the most bizarre, all action dreams – um -<br>Ok.<br>I'm not a particularly adventurous person, but I was, in my dream.<br>(Laugh)<br>And I was doing ama-zing things (Laugh) I was waking up very tired – um-<br>So I - I said can I take it in the morning.<br>And I did take it in the morning for a long time and then the GP explained<br>that really to get and benefit from it - I needed to take it in the evening.<br>Ok.<br>So - I've, I've changed that.<br>So I have that in the evening. | Side effect dreaming, asks GP to change timing. |
| | I mean I just have to make sure that I try ah – eh – A tip that I got from a pharmacist<br>Which I think is wonderful. I can never, ever swallow medication, never -<br>M-huh.<br>But he said, if you pop a grape in your mouth<br>Concentrate on the grape, put the tablet in, just concentrate on the grape, it'll be fine<br>And it is - it works a treat | Swallowing difficult resolved by grapes. |
| **<u>Continued Living – reaching 'Plain Sailing'</u>**<br>'Slow Climb '<br>From Progressive to Stable | | |

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**Han S**

| Stage | Quote | Notes |
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| **Returning Home – ‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | The having a heart attack, I suppose, and then.<br>The consultant saying ‘thou shall take these tablets for the rest of your life blah blah blah’.<br>Yeah, and could you describe that a little bit more?<br>I don't think I've got fear of having another heart attack. No, I don't. No, I don't think so.<br>I hadn't, but there was a one and I, you know, got back onto an exercise routine of some sort.<br>And got back into a routine, life again then.<br>Then you know, I don't think of that as a future thing to happen to me.<br>And when you were started on them, could you describe a little bit more how they were introduced to you?<br>There's a prescription Mr. S. Go away and get it fulfilled.<br>So there was no.<br>Obviously, the doctor explained what each one does.<br>I had a, as part of the heart attack, I had one stent fitted by the way.<br>Just to help things along in the future. So yeah, he explained.<br>When they were and that that routine, that to thou shalt take tablets,<br>was reinforced in the heart attack rehabilitation, ah course, if that's the right word which was about two or three months of sort of lectures and | Directed by consultant.<br>No continuity of care.<br>Obligation to take reinforced in rehab – system factor. |

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| | exercise routines and things like that. | |
| | Well, I hadn't regularly taken any medicines before that, except for things like paracetamol for headaches and back aches and things like that.<br>Not too sure, whether it was a shock, no. That it wasn't a shock,<br>just the doctor said you've got to do this and I I succumb to the. Uh-To the instruction.<br>I mean, did you find it hard, or is it just something you did?<br>I don't.It wasn't hard, it's just getting into a routine and also the last, I suppose four or five years I have been reading up on various books on whether all these tablets are uh-necessary. | Not taken anything previously. Easy adjustment. Imperative to follow directions. |
| **Balancing Pros and Cons** **'Nobody wants to rock the boat'**'Fits and Starts' Regressive to Progressive back and forth | No, I don't. I don't deliberately forget to take them.<br>I don't think, but there are certain circumstances where I don't take the evening ones.<br>If we go out at night in the evening, or.<br>Something happens or we have people in.<br>Then the evening ones don't get taken, and if we perhaps go away<br>the weekend something like that, then perhaps even the morning ones don't get taken, but I've no- what's the word?- Rabid - desire to take tablets every time without questions?<br>So if they get missed. They get missed.<br>And when you've forgotten to take them or when they get missed, uhm, how do you feel? | Not concerned with missed doses. Considers that 'bank' of continued taking balances out. |

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| | Well, generally speaking, I don't like taking tablets, so if I miss them,<br>it's just a shrug of the shoulders. Thinking doesn't, doesn't doesn't, doesn't affect me, I don't care.<br>I don't think that missing one out of three hundred and sixty-five or<br>However many it is gonna make much difference.<br>I am, certainly with statins not particularly convinced that they're working to my benefit so.There you go | |
| | Uhm, so certainly in the annual medical I have with my GP. Well his staff.<br>I would always want to question the size of the tablets and whether.<br>These tablets are still still, still still necessary.<br>With a view to perhaps if there was a smaller tablet of the same sort.<br>I could get away with taking that,, so which I suppose feeds right  back into the idea that if if I miss a day, then I don't really worry too much about<br>Yeah, yeah, and what does your GP say to that does he-?<br>Well, he's operating from the consultant's hymn book isn’t it? and that this is the right mix of medicines to keep you alive for the next few years.<br>So I don't think. We've come to any, we don't have any proper discussions about it.<br>That's the trouble. | Query with medic over dosage/ size?/ need to take.<br>GP has no power over the consultant’s decision<br>He feels frustrated as a result.. |
| | [re: support group] Do you talk about medicines much?<br>Not too much, I can't recall too many serious discussions | Inspired by man who stopped all his tablets. |

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| | about medication, say apart from the chap I met in a shop a few years ago who suddenly decided to stop all his medication.<br>Most people are of the grumbling, uh, about taking all these tablets then so.<br>It's a bit like everybody's congratulating themselves on being the same isn't it?.<br>We're not, no nobody put their head above the parapet and saying in the group that I talked to about this perhaps that are hell bent on not having any one, or all of the tablets?<br>So you find that the group is a support to you?<br>Well, it's a negative support is that much.<br>OK, actually if you could call it support in in that sense that nobody rocking the boat too much.<br>Yeah, I mean, do you, get anything else out of it from going?<br>Not really, I think.Sort of soldier on, I suppose.<br>It's uh. You go away from a situation like that. And think well, I I sort of should've stood up and be counted more strongly than you do at the moment, but I mean.<br>Shrug of the shoulders and laissez-faire attitude, you know, that's the way it is, carry on. Really. | Desire to reduce medication, but social directive is to remain quiet and continue. |
| | Ah, well, yes, you've yeah. Just just said just now that.I wasn't going to rock the boat, really. Unless something I don't know, unless I'm not too sure what what I mean by something serious happened, I wouldn't rock the boat too | His concession to rebellion is to not worry about missed doses. |

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| | much, but I'd rock it a bit like not worrying about not taking them. I mean, if I went away for the weekend and forgot the forgot the. Forgot the tablets to put it in the suitcase then I wouldn't.And I wouldn't worry.<br>Wouldn't even dream of the thinking that you need to take two instead of one the next day. But I would I would continue just to read everything that comes across. That is suggestive, or about the tablets that I take and the conditions that I've got.<br>Just to see whether it would affect me. | |
| | I don't know, maybe just.We've just sort of potter along in some ways, and things coast along Coming in, just hold 30 seconds.<br>Yes, sure.<br>3 way conversations sometimes. Oh yeah.Oh yeah.Yes so, as well as. I think the thing that my wife has just reminded me of the probably the reason why. We we signed up or I signed up for you is. That I'm, already well, both of us are already on a, on a trial that my wife just finished a trial with with blood and I'm in the middle of a trial with with statins.<br>So I think we're probably pretty pragmatic about it all.<br>uh-huh.<br>I'm I'm having a trial with, for a one for one dose every six months instead of a tablet every night. And that's been going along for three, three years yeah. | Everything remains the same, but participating in clinical trial to see the difference. |

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| | And you volunteered for that er, as, something you wanted to do?<br>Yes, yes. Well yeah, it it did. Came across I spoke I I was at the right time with the right set of conditions.<br>And people were were looking for volunteers so I put my hand up.<br>It it doesn't put me out in any way, just half a day of my life every four months now,<br>Just to travel to the next town for a blood test and, uh an injection that may be a placebo, of course.<br>Yes, yeah. So they there's a blood test and. And the injection.To the stomach.<br>That's so interesting. And did, were you experiencing like, problems with the daily statin then?<br>Yes yeah | |
| **<u>Crisis Point – 'Man Overboard!'</u>**'Existential Crisis'<br>Regressive to Progressive and then some | ...were you experiencing like, problems with the daily statin then?<br>Yes yeah, I I got to a point where I was having the version of nightmares. Early in the morning when I got up, woke up about five then I'd go back to sleep and have a. A mild nightmare.<br>And I just went on day after day and so. I went through a period then when I wasn't regularly taking statins.<br>And until I got my act together in terms of how to present it to the doctor and then after a while. An interview with him.<br>Then he changed the variety from simvastatin to the atorvin variety.<br>Which don't appear to cause those sort of dreams or | Side effects of nightmares from atorvastatin, built a case of evidence to take to GP, who changed to simvastatin. Refer to newspaper medic who discussed statins, can't remember which way round it happened. |

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| | nightmares, whichever,I like to call them.<br>And what made you think it was the statins, that were causing that?<br>Ah! I'm, I'm an avid reader of the Daily Telegraph Doctors man.<br>Who produces all sorts of letters from readers and stories and suggestions and things. Sorry he wrote a book about taking tablets, but principally aimed at statins, so perhaps he indoctrinated me as well so it was then that I don't know.<br>Perhaps coincidence I got start nightmares as well as not taking them to. I don't know which came first. The chicken or the egg. | |
| | I haven't no that the the the routine from heart attacks is. After a few weeks or a few months and.then you get signed off if you were being relatively OK, then you get signed over to your GP and so I've only had only seen my GP once since then since 2012 when I.<br>I dropped off the, this one the lansoprazole.<br>Where, which were really by luck really. That I the same times I'm seeing him, I had the symptoms that were being caused by lansoprazole.<br>He, by coincidence, had had some further information about the effect, that lansoprazoles, and they came together. And we stopped it, or he stopped it.<br>And yeah, I mean what's what was that effect?<br>That I was suffering from diarrhoea and. And talking to consultants he suddenly though, this come up and said | Gradually become stable, signed off.<br>Side effect of diarrhoea from lansoprazole, stopped by GP. |

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| | Ah, I've read some reports, it was as simple. Or as daft as that? We stopped or I stopped taking them then. | |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | Well, no, really 'cause. What's come out of the last three quarters of an hour really? As far as I'm concerned is that just taking tablets? its its just a routine now.<br>It's it happens night and morning. It happens, I don't really think too much about it. It's just habit To get up. Make a cup of tea, fix the first couple of tablets, one to dissolve one to stand by at breakfast, have the tablets. And then sometime in the evening. Sometime between. I don't know. between eight and eleven then I'd. have the next lot. Of the evening sort of tablets. It's just a habit now, unfortunately. | Routine is easy habit to maintain. |
| | There's no difference really. Your earlier, just I'm just relying on the consultant. And now the GP from. Saying, patting me on the head. And saying this is what you should have Mr. S. And go away so. Yeah, that's it.Yes, I suppose it's I still have confidence that they're doing the right thing for me,<br>despite the fact that I don't, really like, purely from the point of principle, to take this number of tablets.<br>OK, and could you describe that, that principle that.<br>Sorry, to describe the principal?<br>Yeah, yeah, like you say you don't want to take them. What's it about taking them every day that you don't like? | GP reinforces that he's been a good patient, trusts that he has his best interets in mind, but worry about all the medication's effect.<br>Waiting for another symptom to come along, will blame medication. |

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| | Well, I suppose yes, is. The thing that particularly like,in the back of your mind.<br>There is the idea that perhaps. Combination of four tablets might be in some way, debilitating in, in other ways. Unfortunately, the book I used, this bible, it's full of examples of men and women. Taking tablets and having all sorts of things going wrong with them. On top of what they had to start with so.<br>I don't think that I can blame all the tablets on. Onto my arthritis or my knee.<br>I am just sort of, sitting back and waiting. For something to happen, perhaps.<br>Something different, a different symptom maybe?<br>Well, yes, but I hope not. I think if something did happen and then I would certainly put it down to taking tablets for 10 years.<br>Yeah, nothing so far has been like that and I I. Can't I don't think I'm blame CLL [leukaemia] for that. | |

**Lea S**

| Stage | Quote | Notes |
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| **Returning Home – ‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | Well, I just when I woke up in hospital there was all these tablets in little pots by me bedside.<br>And and I assumed at the time that's what I had to take.<br>And then while I was in hospital, they did come round and asked me if I would help with the drugs trial.<br>Obviously I said yes 'cause I. I was then I was 81 then.<br>Well, I've never been on medication until this happened.<br>And yeah, I mean, how did you feel about having them? | Awareness in hospital of medication. Signed up for clinical trial.<br>Never taken medication before and unhappy about it. |

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| | I don't like taking them. | |
| **<u>Crisis Point – 'Man Overboard!'</u>**<br>'Existential Crisis'<br>Regressive to Progressive and then some | | |
| **<u>Balancing Pros and Cons 'Nobody wants to rock the boat'</u>**<br>'Fits and Starts'<br>Regressive to Progressive back and forth | Yes, yes, but like I say, if we go out of a night I I like to take my tablets round about eight o'clock.<br>But if we go out for a meal.<br>Or it's not easy and then you come home and you chat.<br>And then you're in bed.<br>And you say, oh God, I've forgot to take the tablet.<br>I wouldn't say. You know, I regularly forget, but there are occasions that you forget.<br>It's the situation, isn't it?<br>But you don't worry about missing them?<br>Yeah, yeah. I'm 87, do I care? | Forgotten dose when out for an evening.<br>Chides herself, but doesn't care – she's reached a rebellious age! |
| | I mean, are you concerned by taking them?<br>I don't like taking tablets.<br>We're not used to taking tablets.<br>That's the thing and. It it became a bit alien to us to. Take them,<br>but now we've. Got into a routine that we just take them<br>And what makes you take them?<br>I wouldn't say it's fear.<br>Just the fact that. Somebody more clever than us, that knows what they're talking about and we don't,<br>and they say take them for your good. So we take them for our good.<br>Yeah, yeah. And are you concerned by taking them?<br>Yes, a little bit. And it makes you wonder what poisons are going in your body. | (We) The idea of taking tablets is unusual for them.<br>Chemical concerns.<br>But they've made it a routine.<br>Follows medical directions as medic intentions assumed benefit to them.<br>Questions remain unanswered, concerns swept away by medics. |

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| | Yeah yeah, I mean, do you find out information about them?<br>Well, I frighten myself to death now and again reading the leaflets,<br>and I've stopped reading them.<br>Did you find your information at the start or?/<br>Well, one of them, one of them's for . The stomach<br>or what's the stomach got to do with the heart?<br>And did you ask anyone about that?<br>Yes, and all I got was, you're on the right cocktail.<br>OK.<br>They do my blood pressure. I've never had blood pressure, so why am I taking tablets for blood pressure as well?<br>That, that's what I can't get through to them. | |
| | Well, at 2.9 my cholesterol. Why is my tablet an 80 MG when my husband cholesterol is higher than mine and he takes a lower dose?<br>That doesn't make sense<br>Yeah, yeah And does anyone in surgery listen to that at all? Or you just don't start?<br>All I keep, they keep saying you're on the right cocktail.<br>Right, yeah, yeah. That is quite hard.<br>Yeah, but like I say it would be nice if somebody could sit down with you<br>and and go through everything with you and tell you about things and and why. Why is this and why is that? | Questions about taking cholesterol tablets. Ignored by medics. |

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| | They haven't got the time, there's no way can they do it, really? | |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | No. I'm signed off there, yes?<br>Yeah, and nothing like this simvastatin isn't giving you any side effects or problems, so they're not changing anything in that way.<br>Like side effects that I know of at the moment, but these things take time, don't they? Let's see.<br>Yeah, yeah.<br>You could have a side effect within a week, or it's another side effect after a year.<br>Yeah, yeah.<br>So you can't tell really. | No medication required changing.<br>Side effects take time to occur, so waiting for next thing to happen. |

## Maria U

| Stage | Quote | Notes |
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| **Returning Home – 'Anchors Away'**<br>'Out of the Gate'<br>Regressive to Progressive gradually over time | At the time, at the beginning.<br>It was all very overwhelming | Initially a lot to manage. |
| **Balancing Pros and Cons 'Nobody wants to rock the boat'**<br>'Fits and Starts'<br>Regressive to Progressive back and forth | At the time, at the beginning.<br>It was all very overwhelming, but now my my thoughts are, if you need a pill, take it .<br>If they say you need to take a pill, take it, as what's the option?<br>Keeling over, you know?<br>Like an old car. I always tell everybody.<br>My body's an old car now, the engine. Needs A bit of help and I went.<br>I mean I'll think about it and I'll read up about it.<br>If They introduce new stuff, but, You know if they say I | Restricted choices, need to take medication.<br>Car analogy, prevention from dying. |

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| | need it. I'm not going to not take it. In case I did need it. And you know I think I am somebody that looks into it. | |
| **Crisis Point – 'Man Overboard!'**'Existential Crisis'<br>Regressive to Progressive and then some | The statin was the rosuvastatin.<br>Was that just because the hospital told you to?<br>No, no. I was getting pains in my legs.<br>OK, right.<br>And we tried various, various other ones and then.<br>I don't know. I can't remember why I went to the hospital.<br>I think it was to do with them. Making sure that, you know, that the heart was clear of cholesterol and all that sort of thing. I'm sure it was with the heart doctor, but anyway. Because when it it comes on prescription, they put.<br>Rosuvastatin 'prescribed by the hospital' because<br>I think they like to put you on a cheaper one, don't they, if they can<br>but they make it clear that<br>This has been prescribed by.<br>The hospital, not the doctor.<br>OK.<br>Or the change over, you know. Yeah, yeah.<br>I don't know if it's a particular One that.<br>They don't give out readily unless they need to. Uh-huh. Cheaper, cheaper versions. I think they'd rather have you one,<br>which I agree with, but I think they put 'as prescribed by hospital'.<br>So they don't give me another one instead.<br>Right. Yeah and I had a lot of lower leg pain. | Rosuvastatin caused side effects of pain in legs.<br>Collaboration with GP. |

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| | You know, between knee and ankle, suddenly.<br>And I've never had pains or troubles with me, legs at all, you know.<br>OK. Yeah.<br>The Doctor and myself thought probably thought that.<br>And then the hospital.<br>Changed me over. | |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | And lots of things and life is.<br>If anything a bit too busy sometimes.<br>I do just wonder was I ever got completely back to be normal?<br>And that's the surgery rather than the heart or anything to do with your circulation.<br>Yeah, only that the heart they had to take off all heart tablets for.<br>Those five days and re,<br>Re-introduced them very slowly because all.<br>They said, all have had the potential to have a thinning element to them.<br>Although I'm not on warfarin or anything like that.<br>But they immediately took me off them because.<br>of the risk, they moved it and something else. Everything.<br>They took them five days to reintroduce everything<br>They did it slowly, one or two pills at a time.<br>And did that concern you?<br>What concerned me that<br>I was off them. Yeah, started to get palpitations and being a bit hot sometimes. And you know, but they were monitoring me.<br>They were aware of it, I'd had Two very major operations, you know, but by | Reduced stamina, but presumes that this is the new normal, accepts aging as restrictive. |

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| | the, this happened at the first operation<br>Tuesday. So I was taken off them on Monday, Saturday afternoon the last one ..<br>OK.<br>And yeah, everything, you go back to your normal routine after that.<br>Yes .OK.<br>So that's why I say about a 76 year old.<br>You know I'm very active.<br>Do I know I was 76 year old.<br>Should I feel and that's where something like that and COVID ,<br>will I, is this the new normal though I'm not quite though, I've not quite as much stamina. | |

**Mark K**

| Stage | Quote | Notes |
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| **Returning Home – ‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | Only try and get get a routine.<br>In a way.<br>Putting the the medicines out of their packets, I do first thing in the morning<br>and I've I've got a little pot that I put the mid day ones in the morning at night.<br>It's the last thing I do before going to bed.<br>It's it's. Suppose it's a routine that I try to remember to follow.<br>If I'm on holiday.<br>I guess I am reminded because my wife.<br>Quite literally says ‘Oh, I'm going to have my medicine medication now’.<br>That reminds me.<br>I've got to get my bag of medication out.<br>But they're all in a bag, in a single bag. | Build a routine.<br>Adjusted when away from home |

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| | Which came from the. Hospital when I had the hip replacement. | |
| **Balancing Pros and Cons ‘Nobody wants to rock the boat’**<br>‘Fits and Starts’<br>Regressive to Progressive back and forth | Uhm, the other day we went out for a pub lunch and I didn't remember until about tea time after which I took them then But sometimes I completely forget.<br>Yeah, how do you feel when that happens? It doesn't make me. It doesn’t make me, in a physical sense, feel anything at all.<br>Really, it's just it's just a slip of the memory and I suppose at the age of 81 it's easy to forget these matters. | Away from home, delayed dose. Sometimes forgets, but doesn’t worry. Blames age! |
| | I suppose I could. Write to the doctor. It is writing now because it's so difficult to see doctors, so I I do write occasionally asking queries about whatever with the doctor. And he answers me without any problem. | GP answers his written queries. |
| **Crisis Point – ‘Man Overboard!’**‘Existential Crisis’<br>Regressive to Progressive and then some | I just trusted them, actually I felt that they knew what they were doing and had no problems.<br>Just got on with it. When I did have problems with the cough with ramipril and the GP. Listened to, listen to my complaints and after a while Uhm, thought I ought to go on on the losartan instead.<br>Which originally, as I said, was a much higher dose.<br>After the hip operation, it was a much lower dose as I think I said earlier. | Ramipril caused side effects of cough. Complained to GP who amended to losartan. |
| **Continued Living – reaching ‘Plain Sailing’** | I have no worries at all. | Has been stable since. |

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| ‘Slow Climb ’<br>From Progressive to Stable | Since I've been taking them, I've been very, very stable.<br>OK.<br>That's all I can say. I don't have, I haven't had a bad angina attack, although to start with I was very anxious that I might get another angina attack, but I haven't had one. Because it really was quite dramatic and I. I went in. As an emergency. When I had the angioplasty because. The whole thing was out of control.<br>Right.<br>It was unstable angina. | |
| | The GP takes care of me.<br>OK.<br>Like once a year I go for a blood test and a nurse runs through everything.<br>I did go for a final assessment by the cardiologist and he put me on to the GP,<br>maybe three or four months after the angioplasty.<br>OK. And you're happy with that, do you feel that's enough?<br>Well it it it seems to work, it's now. It's enough. Was three or four years since the. The problem. | Regular monitoring by GP, signed off hospital care. |

## **Ola T**

| Stage | Quote | Notes |
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| **Returning Home –**<br>**‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | When I got home I was sent home. With nothing just these tablets and 'take them',<br>so I felt very very lost and abandoned and afraid when I first came home.<br>We both did [Husband] and I,<br>I felt like we've been just.<br>Put out there and that was it,<br>because the cardiac arrest's a scary thing. But then I started to question things and looked | Lack of continuity of care.<br>Felt lost, and fearful.<br>Same with husband.<br>Found information and learned for herself. |

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| | into the tablets myself and ask questions, and, uh, I had. | |
| | I knew I had to take them.<br>I knew it was important for my health.<br>For my life, and both [Husband] and I are really sensible and we do things as we call ourselves team [T]. That's our surname, haha, Yeah, and we we sort of do things together. [Husband] was very, very nervous. He didn't know how to cope at first but we worked it out. And fortunately, one of our daughters is a nurse. And she was very helpful. | Unsure how to proceed, but worked it out. Social support from husband and daughter. |
| **Balancing Pros and Cons ‘Nobody wants to rock the boat’**<br>‘Fits and Starts’<br>Regressive to Progressive back and forth | Only from going through if I'm given something new and I haven't had a satisfactory explanation, I'll look it up now.<br>ANd then I'll go back.<br>and have a talk with my GP, yes.<br>Yeah, I don't just accept it Willy nilly, yeah?<br>It's my body.<br>I want to know what I'm putting in it.<br>I think it's only fair that you should your GP or consultant or whoever you're seeing should explain to you what it's about, so I would. Question it anyway. | Continues to find information for queries.<br>Asks GP |
| **Crisis Point – ‘Man Overboard!’**‘Existential Crisis’<br>Regressive to Progressive and then some | A few problems with some of them, and there was some. They gave me, which made me very ill.<br>Very, very sick and.<br>I mean really. Projectile vomiting-type sick and others which gave me a hacking cough.<br>So over a period of time with the doctors and consultants, we worked out. | Side effects of sickness, hacking cough. Worked together with doctors and consultants (long timeframe?) to find cause and find more suitable medications. |

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| | Tablets which were suitable for me.<br>And I'm still on those today With a few tweaks here and there. | |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | I have them in a pill sorter box. A Dossett box.<br>OK right Yep.<br>And I do that on a weekly basis.<br>[Husband] and I check them off. Together so we both. Do it to make sure it's correct.<br>And we do it on a weekly, the box on a weekly basis. Yeah, I also have a GTN spray and I have a.<br>Spray for my asthma.<br>A Ventolin.<br>OK yeah yeah.<br>I'm well medicated.<br>And do you ever tend to forget them?<br>No, no, I've never forgotten.<br>OK, that's excellent.<br>I have a box in. The car with um, some in, if I'm out and about. I have them in the car. | Repeated activity, preparing for all events. |

**Pat W**

| Stage | Quote | Notes |
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| **Returning Home – 'Anchors Away'**<br>'Out of the Gate'<br>Regressive to Progressive gradually over time | Did you have anyone in hospital to explain to you what you were going to be taking?<br>Yes, I mean they said, you know, I'll be taking these and at the time, with at the time, no expiry on them, but obviously.<br>As my condition changed and having bypass operation, they obviously did change over time. | Initially told taking long term, in order to prevent another AMI.<br>Nurse checking – infantile. That he's taking them but also monitoring meds are working. |

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| | So when you got home, did you just just get on and take them?<br>Yes, basically.<br>I mean, you know there was no, I did see a heart nurse for a period, a couple of months coming to see me<br>to make sure that I was just being a good boy and taking them and you know that they Doing the job they were meant to.<br>OK. Yeah, yeah.<br>And yeah, what's what prompted you to start taking them.<br>And because they would prescribed to me, you know, at the hospital after I've been admitted having a heart attack. | |
| **Balancing Pros and Cons**<br>**‘Nobody wants to rock the boat’**<br>‘Fits and Starts’<br>Regressive to Progressive back and forth | But you know I wouldn't.<br>And the last thing I would do is look at the Internet to find out what tablets are supposed to do.<br>I feel that quite often one of the worst things on the back of the tablets is the information sheet that goes with it.<br>I always quote the fact that you know that most medicines state it will cause Constipation or diarrhea.<br>In my opinion, they're two complete opposites and it's the body that does it, not medication.<br>So it depends how you react.<br>And going way back to 2003. What kind of information was available at that time? Do you remember?<br>Well, I was certainly told that that, you know, the medication I was given was for my benefit. | Side effects info conflicting doesn’t check but has knowledge. No meds have caused him problems. |

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| | And you know, if there was any at the time, known prominent side effects, I was informed about those.<br>But I did never suffered anything with them, fortunately, I suppose that.<br>OK.<br>None of the medications that I've had over the years.<br>Haven’t caused many major problems. | |
| **Crisis Point – ‘Man Overboard!’**‘Existential Crisis’<br>Regressive to Progressive and then some | | |
| **Continued Living – reaching ‘Plain Sailing’**<br>‘Slow Climb ’<br>From Progressive to Stable | I haven't had anything that's caused me any concern.<br>You know, I say. Certainly not the harm side.1<br>I mean, Touch wood very firmly and say that you know, since I had the bypass operation, after necessary recuperation, I've been very well indeed.<br>I do carry a nitrogen spray. Which I've just renewed, but I haven't used the previous one at all.<br>OK. Yeah. And yeah, things like the ramipril.<br>That's just recently been stopped. Does that sort of. I mean, what does that make you feel?<br>If it's just stopped suddenly? And changed.<br>Well, I haven't.<br>As I say, I've had variations in things over the course of time in the past I've taken, mainly decreasing until finally removed. As well.<br>OK.<br>Because obviously they weren't deemed necessary.<br>Yeah, yeah. | No other incident happened.<br>Some medication stopped.<br>Aim to continue living. |

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| | And and do you sort of think that you rely on those medicines at all or is it?<br>Well, I suppose that I regard them as part of, you know, my treatment.<br>Ongoing through the years.<br>So what would as a treatment, what would your aim be overall?<br>Well, to live as long as possible. Basically. Haha.<br>Yeah, yeah, that's great. | |

**Phil H**

| Stage | Quote | Notes |
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| **Returning Home – ‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | But I learned it in the army. Hahah<br>But my wife's view is that it's my problem if I miss one, and I'll probably discover it the following evening, say. in the nighttime routine. And there I am Thursday, staring at Wednesday's pills.<br>Yeah.<br>Hahah, It's just finger trouble, I'm not perfect, you know.<br>Yeah. | The Army formed his character.<br>How he’s viewed by his wife if he misses dose.<br>‘Finger trouble’ idiom - operator error for forgetting. |
| **Balancing Pros and Cons ‘Nobody wants to rock the boat’**<br>‘Fits and Starts’<br>Regressive to Progressive back and forth | Uhm, going back to this issue, I obey the last orders. Two visits to the [Provincial] hospital and [Capital]. They suggest something. Are you happy and it's either a yes or a no. If it's a recommendation from a serious medic, invariably the answer's ‘Yes. Go with it’. So we've got ongoing improvement.<br>Yeah.<br>If you wind the clock back a number of decades, I had to learn a lot as I went along.<br>Yeah.<br>But that's a different scenario. | Follows directions. Obeys. Qualification of medic is important, persuaded by status.<br>He’s learnt along the way to inform himself. |

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| | It's cause and effect.<br>Reluctant to change it<br>OK. And so having-<br>What I did do at one stage, talked to the nice Asian pharmacist.<br>Wondering whether I should be on the right number of grams of allopurinol.<br>And we dropped it from 200 to 100.<br>And that was a debate between the pharmacist and the Doctor,<br>And we agreed that make a reduction.<br>I haven't had gout since, so I think it might have been under review, but I think that's what they call routine monitoring. | Query dosage of allopurinol. Changed in collaboration with GP via pharmacist. |
| **Crisis Point – 'Man Overboard!'**'Existential Crisis'<br>Regressive to Progressive and then some | Uh, especially with the statins I was getting a lot of aches in the lower limbs. And I raised that with people at Capital and they said, you know X, Y and Z, you know. You don't need to take them.<br>You could if you wish.<br>But not necessarily in your case.<br>Do you take advice before you stop them, or is it just?<br>Yes, I tend to obey the last order, but if there's a problem, you raise it. So, for instance. I used to take Beta blockers.<br>But, um I raised it with Professor M. Who is my cardiomyopathy advisor.<br>What would happen, I'd be dozy in the day, and wake up, about three in the morning. Ready to get up and run a mile<br>OK.<br>And I said it's not doing me any good.<br>OK. | Side effect of muscle ache in legs, so statin stopped by consultant, but he was given option.<br>Beta blocker caused alertness at night, stopped by consultant. |

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| | He looked at things and said, 'No - You don't need beta blockers'. So stopped taking them. | |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | Um, I get an update every time I go to [Capital]. Every time I go to the [Provincial] on the six-monthly thing. The routine at the moment seems to be you seem to be OK. On the basis of an ECG and um, whatever it is. Echo and ECG are they the same thing? Whatever, you do a couple of tests and they say 'no, you seem stable'.<br>And I say 'great'. Haha. | Regular check ups at two hospitals, happy with continued stability. |
| | Yes, I mean like. Sense of I don't know what comes back, what comes next. I seem to be on this plateau, uh. Unless something else appears.<br>Yes.<br>A new symptom.<br>uh-huh.<br>Then that'll require a new initiative. I seem to be happy | Plateau – high up and level. Waiting for another symptom to appear, but happy now. |

**Rod F**

| Stage | Quote | Notes |
|---|---|---|
| **Returning Home – 'Anchors Away'**<br>'Out of the Gate'<br>Regressive to Progressive gradually over time | But the way that I the way that I arranged this, it's it's never a problem, never an issue. The only time I ever miss when it was suggested that I take. tried, I'm not sure whether it was the ramipril, or the enalapril? Whatever, but it was suggested I take one of them at lunch time and so<br>OK.<br>Of course, lunchtime is not the time I. Usually took tablets.<br>So so I didn't. Haha. | Has organised a method that taking meds works.<br>Change of timing cause omission issue, but soon changed back to more routien time. |

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| | Well, I did occasionally, but I didn't last very long because they were they were moved to morning and evening. | |
| **<u>Balancing Pros and Cons</u>**<br>**<u>‘Nobody wants to rock the boat’</u>**<br>‘Fits and Starts’<br>Regressive to Progressive back and forth | It's a fairly new drug. It's quite expensive, but it was designed to. uh, increase the, Sort of the output from the heart. It remodels the heart over The period of time. And that's appeared, which I'm going through at the moment, which is sort of under question really, because in my mind I have I've had. Certain sort of. Well, I think there were some side effects from the Episto, which er. I'm not sure I it's it's. under debate at the moment. I'm sorry, it's not Episto. It's Entresto. | Changed to Entresto, but querying it’s causing side effects.<br>Knows it’s expensive! |
| | I've never been sure that my cholesterol is that high.<br>It's done presumably just to keep my arteries clear.<br>But there may be other statins that they could use. That didn't have the same effect, but this constant runny nose and the lack of taste that I've experienced in my. My sense of taste and smell has gone. So that I have to spice up my foods and in order to enjoy them so. Little things like that. Tend to make me. Look aside at drugs like atorvastatin. I'm looking through all the side effects are again I shouldn't be reading all these leaflets and doing the views on the internet and so on, but they're all little significant points to me, which I'm thinking. Well could that be improved? | Wants to refine the statin he’s taking as it causes taste and smell disturbances.<br>Thinking, but not taking action. |

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| | But you know, it's it's so difficult. Really, I don't like. I don't like to challenge professionals in that sense.<br>Um, I'm not the sort of confrontational sort of banging the desk sort of character, that says look.<br>It says this and I I want to do something about it.<br>We do it by some gentle discussion, and perhaps you know, as I say, I then outweigh the effect.<br>The effect of my runny nose or my loss of taste, or my muscular weakness.<br>I I offset that against the benefits that the drug is supposed.<br>To be giving me so. There's this sort. Of compromise in my mind eventually which.<br>I hope will one day be proved. By either long term benefits or. The end of the line. | Doesn’t want to cause a fuss at the GP.<br>He makes a compromise to persist with it, balances with long-term benefit. |
| **Crisis Point – ‘Man Overboard!’**‘Existential Crisis’<br>Regressive to Progressive and then some | Yeah, well I I I've been on various doses of bisoprolol and for whatever reason<br>I know it's a standard drug which is used pretty traditionally in most of these cases.<br>I started on 1.25. I went to 2.5. Uh eventually ended up on 3.75.<br>But I found that my blood pressure was. But it seemed to. Me that I was. I was experiencing postural hypotension and. They did one of the GP's that I saw, not my regular GP, but they decided that perhaps.<br>The bisoprolol had been a bit too active and so it, it went | Varied dosages of bisoprolol.<br>Went too high, causing side effect of hypotension.<br>Asked GP, and got it reduced. |

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| | back to 1.25. But as I said, I'm now on two point five. I divided dose twice a day. | |
| | The postural hypotension that I was experiencing after stopping The ramipril and the. Epirenone and taking the Entresto. And I was getting these sort of little dizzy spells when I walked upstairs. If I bent down. Which is which was a little bit new. It was a little bit more severe than. It had been and. I'm not sure. Whether it's the Entresto. My GP insists that.<br>We can't go tinkering around with it at the moment.<br>We've got to leave it, give it some time.<br>I my my debate with myself now is how much time do I give it?<br>How much time do I? In the time I'm (feeling?) the.<br>Side effects that I feel I'm experiencing.<br>Rather than the benefits that. The long term.<br>Benefits that the drug will give me. | Query Entresto causing worsening dizziness, asked GP but persuaded him to continue for a while longer. He wants to know how long and whether it's worth the offloaded benefit. |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | Uh, maybe 12 months ago, maybe a bit more, and I'd expected the pacemaker, particularly to certainly enhance my activity and then make me feel better. But there hasn't been that sort of result. There hasn't been any dramatic improvement in my health. Or in my. With my medication. I have to measure that against the fact that I'm. Now eighty-eight. And, What can I expect? How much improvement? And we hear all this talk about athletes who don't even start training until they're 70 plus. And | [About pacemaker, but also medication] Has remained stable, but expecting to improve in stamina. Deducts that ageing has also restricted his abilities. |

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| | they push themselves. And they they achieve marathons and so on. But at eighty-eight And undergone. I think. It was a fairly mild heart attack I I didn't think it was a heart attack because I didn't have the sort of chest pain thing I. Just felt very unwell. Well, but having undergone a heart attack of some description. I wasn't sure then just what level? Of fitness I. Could achieve and I'm still. I'm still looking to achieve. I'm still looking to improve. | |

**Ron P**

| Stage | Quote | Notes |
|---|---|---|
| **Returning Home – ‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | The medication in a box in the kitchen. The medication in a box in the kitchen. So yeah. You know, just take tablets and put back into, into the box again. But I keep a store of the rest of the drugs. Elsewhere. You know? When I go away I'd take I’d carry. A little plastic case with different. Little lids for different days. The four pills in for each day. Which keeps it neat and tidy. So yeah, it's it's become second nature, so it's I know exactly what I need to take and when 1<br>So I don't. Need any reminders. Or anything like that. And it works well. | Uses Dossett box, kept in kitchen. Works well, doesn’t need further prompts. |
| | So so yes, I I returned to. I returned home To be honest it’s not really that much of a big deal, the medicines, Just sort of like cleaning your teeth really at the beginning and End of the day, it’s not inconvenienced me at all | Adapting back home, just fitting it into a routine, no inconvenience.<br>Required to plan ahead for going away. |

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| | Obviously you have to make sure, that, I carry the drugs around, if I go away. But you know, it's it's been pretty straight forward. It's not really affected my life my lifestyle too much., really at all. | |
| **Balancing Pros and Cons ‘Nobody wants to rock the boat’**<br>‘Fits and Starts’<br>Regressive to Progressive back and forth | It's hard to tell whether that they're making any difference. So we'll be there with, my cholesterol. Will have stayed low. If I hadn't been taking the drugs and it's just controlled by the diet and the exercise. But so I guess. Again, it's just reassurance thing with that at least. I know that's the statins, are likely to be having a at least. Not not a bad effect, you Know hopefully positive effects. Keeping the cholesterol level at. That good level? | Don’t know whether medication is working. Suggests statins are only producing good effects. |
| **Crisis Point – ‘Man Overboard!’**‘Existential Crisis’<br>Regressive to Progressive and then some | After a little while, they moved me on to simvastatin But I actually had some problems with that in terms of sort of side effects.<br>And so they did. Put me back onto atorvastatin again, After about six months of that. And I’ve been on that ever since then. OK./ The others were all unchanged. | Side effects caused by simvastatin, returned back onto atorvastatin. |
| **Continued Living – reaching ‘Plain Sailing’**<br>‘Slow Climb ’<br>From Progressive to Stable | Over the years there were. A couple of times when the cholesterol level went up slightly. And I did feel. A little bit. Anxious, I guess. Nervous about that. But you know, it just felt reassuring that. I I feel that if if the indicators. Start going the wrong way. They either that | Continued monitoring, watching biometric levels, aware if they change. |

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| | that maybe. Situation was changing. That if it starts I'd have a reasonably early warning in order to take steps. I don't know whether those might be to remedy it. | |
| | Yes, I I suppose I do it because I you know, I I, I don’t. See the obvious benefit from taking them other than the fact that everything stays stable so. If I was taking for example. Paracetamol for. A headache, I'm saying that more to alleviate a problem that. I want to see it removed, whereas with the with the heart medication It's really just. Sort of view it as this shield. That's all. Keeps things, helps keep things stable. | Doesn’t notice an obvious benefit or change by taking medication. Staying stable. |

**Tony T**

| Stage | Quote | Notes |
|---|---|---|
| **Returning Home – ‘Anchors Away’**<br>‘Out of the Gate’<br>Regressive to Progressive gradually over time | I am I am organised. I don't. I don't miss many. For instance, I was told at this time when I was getting, having the problem and in and out of sometimes two or three times a day into in and out of AF, I was told that I had to take my blood pressure every morning. And I do I've got a book which it's kind of. I don't know. Twelve to thirteen years worth of daily records of blood pressure and pulse. So I am. I am fairly well organised, I don't. I don't play about with it. I do what I'm told. | Organised to take medication, evidenced by recording BP. Follows medical directions. |
| | Because I was. Told to take them and if I didn't. / OK.<br>My heart problems would get worse. But only, there's more positive than that, because | Taking to avoid AMI recurrance, but also improve quality of life, due to cardiac complications. |

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| | taking them improved the quality of my life. When you're getting AF. Paroxysmal AF, it's very limiting because you. I mean I've been in hospital abroad. You go abroad and. On a holiday. And you go into AF after a day. In that day get AF, the family starts worrying more than I do. That was unfair, so I do what I'm told. | Concern how his cardiac health worries his family. |
| **<u>Balancing Pros and Cons</u>**<br>**<u>'Nobody wants to rock the boat'</u>**<br>'Fits and Starts'<br>Regressive to Progressive back and forth | I wouldn't know for sure. I wouldn't know for sure, but one of the problems that I've got is very, very dry skin.<br>I suffer from eczema and dry skin and I've put oceans of cream and ointments on my skin every night. Pretty well, over my whole body.<br>I've often thought that maybe, not that the medicines are to blame for that, that maybe they're aggravating that condition. But what problem do I want? So I just get on with it. | Query dry skin worsened by medication.<br>Offset against benefit. |
| | You read these leaflets that come with the with the drugs, and if you they will tell you what the possible side effects are, yeah. That you read..<br>I think you know that's that's the explanation for what I'm experiencing at the. Time it may be, but what's its?<br>If the medicine is generally helping me, keeping me in good health. I'm prepared to put up with a little bit of inconvenience as long as it's not, and I don't know whether it's caused by the drug or just. It's another problem that I've got, so I don't worry about it. Let's just keep taking the | Reads information, knows side effects.<br>Flexibility in tolerance for negatives versus long-term benefit.<br>Hope to keep everything the same by taking medication. |

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| | drugs and living the life I'm leading now. | |
| **Crisis Point – 'Man Overboard!'**'Existential Crisis'<br>Regressive to Progressive and then some | and one time I was put on this rivaroxaban And instead of warfarin, but I suffered a great deal of internal bleeding, perhaps by coincidence. That was in April last year I was in hospital with internal bleeding for the fortnight and they put me back on the warfarin, so I just do what I'm told to do. | [Anti-coagulant] Side effect of bleeding caused by rivaroxaban, 'they' put him back on warfarin. Repeats, following directions. |
| **Continued Living – reaching 'Plain Sailing'**<br>'Slow Climb '<br>From Progressive to Stable | Good, my health is, partly through taking these tablets. So that, and the advice and the actions that I take, but I'm in good health if somebody said to me, are you in good health? I'm in good health. I've got, I'm 82, 83, so you've got to say you've got some sort of limited life left, but it doesn't bother me. I'm, I live a good life at the moment. | Taking tablets leads to good health.<br>Self-care and following advice put him in better health.<br>Has lived long already, it's quality that matters now. |

# Appendix E: Published Articles

scientific reports

OPEN

# A phenomenological analysis of the experience of taking medication to prevent a further heart attack

Hannah Piekarz*, Catherine Langran & Parastou Donyai

**Following an acute myocardial infarction, patients are prescribed a regime of cardio-protective medication to prevent recurrent cardiovascular events and mortality. Adherence to medication is poor in this patient group, and not fully understood. Current interventions have made limited improvements but are based upon presumed principles. To describe the phenomenon of medicine taking for an individual taking medication for secondary prevention for an AMI, Interpretative Phenomenological Analysis was used to analyse transcripts of semi-structured interviews with participants. Themes were generated for each participant, then summarized across participants. Five key themes were produced; the participants needed to compare themselves to others, showed that knowledge of their medicines was important to them, discussed how the future was an unknown entity for them, had assimilated their medicines into their lives, and expressed how an upset to their routine reduced their ability to take medication. Participants described complex factors and personal adaptations to taking their medication. This suggests that a patient-centred approach is appropriate for adherence work, and these themes could inform clinical practice to better support patients in their medicine adherence.**

Cardiovascular disease currently causes over 4 million deaths annually in Europe[1]. Acute myocardial infarction (AMI) is responsible for the largest proportion of these, estimated to be 15% of the total[2]. In the UK, just under one million people are thought to be AMI survivors[3].

Following an AMI, a combination of five different classes of medicines are recommended as part of treatment guidelines for secondary prevention in the UK[4], the US[5], and Europe[6]. A meta-analysis of these drug groups has found that following the five-drug therapy confers a 40% reduction in mortality and 25% reduction in cardiovascular events[7]. Whilst a broader study in coronary heart disease patients, it found that the reduction in all-cause mortality and cardiovascular events was due to an additive effect. This highlights the importance of taking these drugs in accordance with the prescription issued by a health professional.

Medicine adherence is defined as "the extent to which a patient's behaviour matches agreed recommendations from the prescriber"[8]. Meta-analytic data from 376,162 patients has shown the level of adherence in patients taking medicines for secondary prevention of AMI to be 66%[9]. This study found no other statistically significant differences between the drug classes, which suggests that non-adherence is not related to a drug class characteristic, such as a drug side-effect, but to other factors. Because non-adherence in AMI increases one-year mortality, hospitalisations and costs[10], it follows that improving medicine adherence should then reduce patient mortality, morbidity and healthcare system costs.

Improving medicine adherence has been a focus for the World Health Organisation (WHO)[11], which famously reported that "increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments".

In the UK, the standards of practice for the NHS are determined by the National Institute for Health and Care Excellence (NICE), which has produced treatment guidelines for improving medicine adherence[12]. This report acknowledges the need to understand patient perceptions of their medicine along with the physical practical support that can be given to aid patient adherence. It recommends that adherence is supported through patient involvement in decision-making, offering information, and being aware of patient concerns.

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There has been much research into finding effective interventions, yet many are complicated and eventually unsuccessful in terms of improving medicine adherence and clinical outcomes[13]. Most adherence research uses quantitative methods to determine adherence as an outcome, with a thin evidence base underpinning the theoretical framework. A study of the data from adherence studies concluded that most interventions are not produced as a result of theoretical models[14], even though interventions aimed at changing behaviour have been shown to be more effective when based upon theoretical models[15]. Therefore, a qualitative approach would be useful to generate themes and propose models which could ratify conceptual frameworks and direct further work in quantitative studies. Historically, there is a lack of qualitative research into medicine adherence[16].

Consistent with a patient-centred approach, a qualitative phenomenological study is appropriate to obtain a patient perspective of the experience of taking medicines, beliefs, and how patients conceptualise their medicines within their lives[17]. In addition, a study that includes an exploration of the social context and lived world of a patient would be appropriate, and an ethnographic patient interview is suited to this purpose[18]. Interpretative phenomenological analysis (IPA) was chosen as an established accessible methodological framework upon which to base this study[19]. There is debate between the leading practitioners in phenomenology as to the philosophical underpinnings of their own respective methods[20]. In order to develop a deeper phenomenological aspect to this study, the additional framework of existential life-world categories of time, location, embodiment and relationships were used in the analysis[21].

**Aim of the study.** To describe the experience of an individual taking medication to prevent a further AMI, and factors that influence their medicine-taking ability.

**Ethics approval.** This study was approved by the University of Reading Ethics Committee (Reference UREC18/36).

## Method

This study followed COREQ guidelines to conduct the research[22]. A sample size of four participants was chosen to enable a quality analysis to take place, to ensure thoroughness, depth and maintain ideography of the analysis, consistent with an Interpretative Phenomenological Analysis (IPA) study[23].

Participants were recruited using a promotional poster cascaded by email within the University of Reading, which was also sent to targeted cardiac support groups within the locality of the South-East region of the UK. The criteria for inclusion were adult individuals with a diagnosis of AMI and who had been prescribed medication for secondary prevention of AMI.

Initial contact was made through email with the first author, HP, the study information was distributed, and written consent returned in person or via email. Prior to interview, participants were assigned a pseudonym. All participants who made initial contact followed through to full interview.

All interviews were conducted by HP in a private office room, either face to face or over the telephone, between June 2019 and January 2020. The interviews ranged in duration from 17 to 65 min, and average time of 48 min.

A semi-structured interview schedule was used to guide the interviews. The schedule was informed by one used in a similar medicine adherence phenomenological study[24], and more general literature on developing interview protocol[25]. Following the first interview, the schedule was refined in accordance with a self-reflective 'interview the interviewer' technique[26], the final schedule can be found in Additional Information. All listed questions were put to the participants, and during the interview, further lines of questioning and probes were added in response to answers given by the participant as the interview progressed.

Field notes were taken by HP during the interviews as an aid to topic coverage. Immediately following the interview, notes were made on meaning of discussion topics, to aid in the analysis. The notebook was used during the transcription and analysis stages also, to add a reflexive commentary on the researcher's thoughts and sense-making process.

Interviews were audio-recorded to MP3 file, which was transcribed verbatim by HP into an MS Word text document. The transcripts were checked alongside the audio to confirm accuracy. In line with a transparent study, participants were sent a copy of their transcript. No participants disagreed with the content of their transcript.

Analysis was undertaken according to IPA[23]. All transcripts were analysed by HP, a novice qualitative researcher, PhD student and practicing pharmacist. The transcripts were read a minimum of twice, and line-byline notes made using an IPA stance, a description of the meaning and understanding by the researcher of the participant's statements. The first transcript notes were discussed with PD, an experienced qualitative researcher and Professor of pharmacy practice, with specialisms in anthropology and psychology. This discussion generated further notes, consistent with a "mini-independent audit"[23], a check of validity. This discussion of notes was repeated for the second transcript.

Life-world framework categories of time, location, embodiment and relationships were used as an initial means of organising and arranging the notes[21]. The transcript notes were colour-highlighted by life-world category and grouped.

Following the first sift into lifeworld groups, the transcript notes were coded into thematic groups, collected together according to concept. These groups were used to write a participant summary document in prose, which described each individual, arranged by life-world category. In line with IPA, preservation of the participant's voice is important, and so the original interview quotes were used to illustrate themes. Analysis was repeated for each transcript and a summary document was produced for each participant.

The summaries of themes for each participant were grouped together, using overarching themes that encompassed all the concepts encoded in the themes that they described. These were the superordinate themes that

| Superordinate theme | Theme | Quote | Transcript line reference |
|---|---|---|---|

| | | | |
|---|---|---|---|
| Comparison to others | Health conscious | Lifelong vegetarian | 44 |
| | | Never taken medication | 65 |
| | | …Because I was living that lifestyle (Re: survival) | 152 |
| | | As fit as a butcher's dog | 169 |
| | Unusual case | Didn't fit the bill for anyone having a heart attack | 43 |
| | | Didn't fit anyone's profile | 48 |
| Knowledge | Medicine information | [Medicine names, dosage and times] | 77, 79 |
| | Question cause | Why had it happened, | 146 |
| | Question medicines | Are they doing what they're supposed to? | 219 |
| | | What would happen if I didn't take them? | 220 |
| | | How does the combination work? | 234 |
| | Self-perception (medicines) | Am I on the highest? Am I on the lowest? | 224 |
| | Self-perception (fitness) | No idea of what level you're at | 176 |
| | Sharing knowledge | I told her what I'd been told | 187 |
| | Strength in numbers | Collective support (re: rehab group) | 234 |
| Considering the future | Planning into the future | To be seen in a couple of years | 172 |
| | Indefinite | Continue to have to take these | 241 |
| | Continuous future | Forever and being compliant | 242 |
| | Unknown future | Not knowing where I was heading… | 152 |
| Assimilation into lifestyle | Overwhelmed initially | Started off with a whole raft of things | 52 |
| | Physical issue | Could never swallow medicines | 92 |
| | Overcome issue | Always have to have grapes | 113 |
| | Taking medicine is unremarkable | It's just a routine now | 107 |
| Disturbance to routine | Being away from home | Can be a bit difficult when you're travelling | 113 |
| | Distracted by activity | Been a particularly busy day, it's not until the evening when I thought, 'Crickey!' | 109 |

**Table 1.** Summarised themes and example interview quotes from Gaye.

featured across all the participants' transcripts. These superordinate themes were organised into tables illustrated with the original text quotes from each participant which are presented in the results section below.

## Results

The participants (n = 4, 2 women, 2 men) were assigned the pseudonyms Gaye (Table 1), Beki (Table 2), Chris (Table 3), and Colin (Table 4). They all described their AMI as a "heart attack" and so this term is used henceforth. All participants lived in the South-East region of the UK and came from higher professional or business-owner backgrounds in their working career. They all initially received emergency care through the NHS and continued their access to healthcare through their NHS general practitioner service. Beki and Chris sought additional care through using private consultant cardiologists.

Gaye is a retired woman, in the age range 60–70 years. She had two heart attacks and considers that her healthy vegetarian lifestyle is the reason that she survived them. She had difficulty swallowing tablets but overcame this by taking her medicines simultaneously with swallowing a grape.

Beki is a working woman in the age range 30–40 years. She had two heart attacks but considers herself an anomaly due to her fitness and young age. Her initial diagnosis was not of a heart attack, it was through her own research that she found a consultant to confirm a diagnosis of heart attack.

Chris is a retired man in the age range 60–70 years. He had one heart attack. He decants all his medication into a Tupperware box in order to save time and hassle. He also takes medication for back pain and restless leg syndrome, for which he adjusts doses according to the severity of his symptoms.

Colin is a retired man in the age range 60–70 years. He had one heart attack, whilst on the golf course and was air-lifted to hospital away from home. Dissatisfied with the quality of transfer of his care between hospital and GP, he sought private healthcare.
The participants discussed medicine-taking through four superordinate themes (Table 5); they *compared themselves* to others, *knowledge* was important to them, they considered the *future* in some form, and they discussed ways that they fitted their *medicines into their lifestyle*. A related theme to lifestyle, all participants discussed how *a change to their routine* adversely affected their medicine-taking.

**Comparison to others.** One of the superordinate themes was the way in which participants focussed on their history and lifestyle leading up to their heart attack in reference to other people, often evidencing that they were in a superior position, and as proof that their body was healthier by managing to survive the heart attack.

| Superordinate theme | Theme | Quote | Transcript line reference |
|---|---|---|---|
| Comparison to others | Health conscious | Training for the marathon | 5 |
| | | Planning on starting a family | 137 |
| | | Never smoked | 259 |
| | | Been this weight since…a teenager | 558 |
| | Unusual case | I'm not kind of, your normal case | 628 |
| | | The youngest person on the cardiac ward | 607 |
| | | I'm not your fat sixty or seventy year-old man | 95 |
| | | My heart function is normal | 456 |
| | | My heart has no damage to it | 458 |
| | Dislike of labelling | I hate that term (re: saying I have heart disease) | 448 |
| Knowledge | Medicines information | [Medicine names, dosages, timings] | 77, 78,79, 159, 190, 192, 222, 246, 248 |
| | Self-perception (medical) | Cholesterol…high for me | 256 |
| | | All of the data | 116 |
| | Seeking information | Load of Googling | 422 |
| | | A bit of PubMed searching | 656 |
| | | A UK Facebook group | 427 |
| | | A lot of my friends are Doctors | 696 |
| | | Spoke to a friend… endocrinologist | 657 |
| | | Sister-in-law is a consultant | 734 |
| | Cynical of care | They were generally a bit rubbish | 99 |
| | | The ECG technician will answer your question | 105 |
| | | Here's a bag of stuff | 293 |
| | | A whole leaflet of aftercare | 296 |
| | | The woman that hands me… probably has no clue | 976,977 |
| Considering the future | Future unknown | Try not to dwell, may happen again | 461,462 |
| | Continuous future | Every day for the rest of my life (re: taking medicine) | 344 |
| | Planning ahead | Lipids done every year | 964 |
| | | Making an appointment | 622 |
| | | Four medicines every six weeks | 648 |
| Assimilation into lifestyle | Consistent location | They're all in the kitchen | 477 |
| | | Down in the kitchen | 375 |
| | Reason for location | Out of the way | 478 |
| | | Aspirin has to go in water | 374 |
| | Child is priority | Had stopped taking the (contraceptive) pill | 156 |
| | | Came off statin, clopidogrel | 177 |
| | | Breastfed him | 186 |
| | | A break while I was pregnant | 971 |

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|---|---|---|---|
| | Concern for partner's anxiety | Look like a battered wife (re: bruising as side effect) | 902 |
| | | My poor husband… | 141 |
| | | woke up, thought I was dead (re: coldness as side effect) | 142 |
| | | I think my husband worries about it more than I do | 442 |
| | Side effect tolerated | For the sake of a year, it's fine (re: clopidogrel causing bruising) | 921 |
| | Side effect unacceptable | Felt like wading through treacle | 138 |
| Disturbance to routine | Being away from home | I think probably I was out and thought, 'oh yeah' | 492, 494 |
| | Distracted by activity | Just didn't 'cause I came home and went straight up to bed | 495 |

**Table 2.** Summarised themes and example interview quotes from Beki.

| Superordinate theme | Theme | Quote | Transcript line reference |
|---|---|---|---|
| Comparison to others | Parallel self | That was the heart attack that would have been fatal | 52 |
| | | And er, if we hadn't gone – who knows? | 85 |
| | | Thinking—I've got cancer | 523 |
| | Comparison to an acquaintance | You know, just passed away on the spot | 66 |
| | Comparison to relatives | I have two brothers. Both younger | 942 |
| | | He had a triple | 944 |
| | | He needed a bypass, but because of his head (re: other brother has pacemaker) | 949 |
| | | We do compare notes between us | 968 |
| | Unusual case | My heart was undamaged | 926 |
| | | My heart had found ways of getting supplies from other channels | 924 |
| | | It was a re-plumbing job—it wasn't a heart repair job, which I think was quite significant | 936, 937, 938 |
| Knowledge | Medicines information | [Names, doses, times and identification of medicines] | 169, 182, 183, 194, 195, 196,<br>223,273, 284,285, 286,474 |
| | Theoretical knowledge | And also one used for epileptics | 180 |
| | | Which is again, a drug normally used for Parkinson's disease | 190 |
| | Practical knowledge | Intelligently, I have, you know (re: self-adjusts dose) | 558 |
| | | Self-diagnosed, self-prescribed | 500 |
| | | Did off my own back | 563 |
| | Follows advice of professionals | I'll stick with that one | 581 |
| | | Wouldn't stop taking that one without taking advice | 582 |
| | | 'Cause it helps with the heart rate | 579 |
| | | If that's what they say, | 976 |
| | | I won't question | 979 |
| | Self-perception (Medicine) | I'm on about as low as you can get | 575 |
| | Self-perception (Medical) | My readings seem to come out OK | 218 |
| Assimilation into lifestyle | Continuing as usual | And I'm taking it when it fits in with my life | 205 |
| | | Just throw in the morning 'cos it's more convenient to me | 217 |
| | | Take them when it fits me | 227 |
| | Adapting to change in routine | And I get on with it 'cos it's only short-term (re: antibiotic course) | 340 |
| | | I'd probably do one of those for the flight time (re: small pill box) | 357 |
| | | It lived in the car all day…Wanted to make sure I had the afternoon ropinirole with me | 368,370 |
| | Taking medicines is unremarkable | Sort of, pick them up, chuck them in and swallow them | 297 |
| | | And taken without thinking | 113 |
| | | It's whatever's in front of me | 292 |
| | | Like having a cup of coffee or a glass of wine (analogy: routine) | 535 |
| | | Coffee for that, wine for this (analogy: cultural) | 1092 |
| | Location of medicine | This square box with a green lid that's got everything in | 361 |
| | | Sometimes it's in the kitchen | 364 |
| | | Sometimes the worktop, sometimes the cupboard | 365 |

| | | | |
|---|---|---|---|
| | Constructed relationship with regular medicines | My normal, you know, cocktail | 343 |
| | | A routine, daily medicines, wall to wall | 1023 |
| | | Doesn't become a part of the family of the rest in my box (re: antibiotics) | 336,337 |
| | | It's a bit of an intruder | 339 |
| | Made own system | Works absolutely brilliantly | 361 |
| | | That's my method | 389 |
| | | Sorry, but that's the way I do it | 391 |
| | Concern for efficiency | A tenth of the time it would the other way (re: decanting medicine) | 433 |
| | | It's very timesaving | 434 |
| | | An absolute disgrace (re: overpackaging) | 415 |
| | Unconcern with adhering to doses | Wouldn't have bothered me | 500 |
| | | None are things that are life threatening if I miss a day or take too many | 464 |
| | | Totally relaxed | 467 |
| | | There's no hassle or stress or anything, on it | 478 |

Continued

| Superordinate theme | Theme | Quote | Transcript line reference |
|---|---|---|---|
| Disturbance to routine | Distracted by activity | Something distracted me and I was doing something unusual late last night, | 483 |
| | | I went to bed and forgot that I'd not taken my pills | 497 |

**Table 3.** Summarised themes and example interview quotes from Chris.

This theme was interpreted as participants constructed a 'typical' heart attack patient profile for comparison in terms of healthy living status, gender, age and type of heart attack. For example, terms like "Didn't fit the bill for anyone having a heart attack", and "I'm not your fat sixty or seventy year-old man".

They frequently gave examples of how they were health conscious. They considered that vegetarianism, nonsmoking, training for a marathon, preparing for pregnancy, and gym attendance to be attributes that made their health superior. They used their own biometric results to compare their health to normal ranges as justification that their health is comparable to 'normal'. They also described similar diagnoses in acquaintances, friends and relatives to discuss how their case was different, with the implication that their case was less morbid. Colin defined himself in terms of luck.

**Knowledge.** The superordinate theme of knowledge encompassed a range of themes that included questioning the cause of their heart attack and need of their medicines, seeking information, having a theoretical and practical knowledge of their medicines, sharing information with others and receiving support as part of a group. The category of knowledge also encompassed self-perception, including participants' understanding of their own medical status, fitness, and medication. The concept of having knowledge was interpreted as an understanding of their body helped participants to regain control over it. Participants commented they "Read the leaflet about what they do and what the side effects are" and asked, "Are they doing what they're supposed to?".

All participants were able to describe their medicines and medical treatments. In addition, they showed curiosity to know about their treatment, either finding answers themselves or using the knowledge of others. Gaye articulated her lack of knowledge about her medicines.

All the participants could recall the names, timings and strengths of their medicines, often referring to paper copies of medical notes during their interview, although these were not requested by the researcher. They found information through hospital consultants, GPs, acquaintances, family, support group and rehab group members. They used sources such as medicine information leaflets and academic-level databases. Two participants sought the knowledge of a private consultant, reasoning that the consultants' professional status conferred a better level of care. One participant linked private healthcare with receiving better care and economic status.

**Considering the future.** This superordinate theme was drawn out by participants as they invoked the idea of the future in all their narratives. This theme was interpreted as constructing certainty and reassurance. The uncertainty of the future illustrated by "not knowing where I was heading". Gaye, Beki and Colin all mentioned taking medicines continuously into the future, using an almost identical phraseology of "having to take these forever", and Beki's "every day for the rest of my life".

Gaye mentioned that the future is unknown in terms of heart health, and Beki considered that another heart attack is possible. Colin used the future conditional tense as he talked about having taken his medicine for such a long time "it had built up inside", and that if he missed a dose, it "shouldn't be a problem".

**Assimilation into lifestyle.** Another broad superordinate theme was assimilation of medication into the participants' lives. All participants relayed how they accommodate their medicines into their everyday routine in a unique way. This group included themes of personal relationships, medicine location, systems and adaptations. This theme was interpreted as fitting medicine-taking to their life-world, a means of control and stability. They used phrases such as "Take them when it fits me", and "It's just a routine now".

Gaye and Colin discussed being overwhelmed initially, but then how taking medication has become part of their everyday life. They both described the routine they had created, now as unremarkable and not noticeable. Both Beki and Chris mentioned a difficulty, Beki because of the side-effect, and Chris because of the extra quantity to remember, but they persisted with their set treatment.

Gaye began with swallowing difficulties but was given a "tip" by a pharmacist, and now takes medications simultaneously with a grape.

The location of medication was discussed as a practical decision or based upon their beliefs. Beki sites her medication in her kitchen, "out of the way" as her son's safety is a priority. Chris decants all packaging and keeps them mixed in a Tupperware box, as an efficiency measure. Colin keeps his medication in a pouch which remains in one location at home, his GTN spray is the only item that he will carry in his pocket whilst at the gym.

Beki discussed how her pregnancy took priority over her medicine taking, as she stopped taking some of her medicines.

Chris and Colin talked about medicine-taking as an effortless activity, both using the analogy of coffee and tea-drinking to describe the automatic nature of taking medicines. Chris compared cultural drinking to taking different medicines, "coffee for that, wine for this".

Neither Chris and Colin were concerned about missing doses, Chris reasoning that missing medicines wasn't life-threatening, and Colin because he doesn't notice any difference.

| Superordinate theme | Theme | Quote | Line reference |
|---|---|---|---|
| Comparison to others | Chance affects health | I was pretty unlucky to have a clot | 469 |
| | | I'm just so lucky really | 729 |
| Knowledge | Medicine information | [Medicine names, doses, timing] | 26, 28, 29, 30, 31, 32 |
| | Seeking superior healthcare | That's when we decided to see the consultant privately | 181 |
| | | For longer than most people would recommend | 76, 77 |
| | | Said 'stay on the clopidogrel for a further year' | 97 |
| | | Even though the reports say that its rubbish | 218 |
| | | He reckons that it's worthwhile | 219 |
| | | This consultant, who I trust, said take them | 390 |
| | | He's pretty well-regarded in his profession | 653 |

| | | | |
|---|---|---|---|
| | Seeking information | Read the leaflet about what they do and what the side effects are | 629 |
| | Self-perception (medical) | Always was fine and always is fine | 147 |
| | | Stable ever since | 161 |
| | | Been settled for quite a long time | 202 |
| | | Not in the last, probably nine years | 505 |
| | | Been taking them for such a long time | 338 |
| | | Drug has built up inside me | 340 |
| | Self-perception (fitness) | I managed a good peak time | 64 |
| | | A very good walking time | 153 |
| | Financial exchange to access healthcare | The National Health wouldn't provide them | 83 |
| | | BUPA don't think it's entirely necessary | 137 |
| | | Certainly our GP, they won't pay for that. That's up to me | 138 |
| | | Surgery stopped paying for Omacor, it was do it yourself, if you want it | 141 |
| | | I can afford it, let's put it that way | 452 |
| Considering the future | Continuous future | I just have to take these forever | 169 |
| Assimilation into lifestyle | Initial difficulty | It was all so new then | 22 |
| | | They just said you're on these, and go | 178 |
| | | Wasn't in the best for a couple of days | 136 |
| | | A bit difficult to know what each one was doing | 37 |
| | | Felt disappointed that I was going to take medication | 172 |
| | Taking medicine is unremarkable | Just as routine as having a cup of tea | 379 |
| | | Just take them and get on and do things | 391 |
| | | It takes 30 s, what's the problem? | 404 |
| | Unconcern with missed doses | I don't notice that I've taken anything | 209 |
| | | I don't get worried if I don't take them | 366 |
| | | I don't notice on a daily basis | 497 |
| | | I miss one then never notice any difference | 501 |
| | Location of medicines | In a little pouch, there the whole time | 293,294 |
| | | Leave them out, just to remind me | 290 |
| | | Take upstairs, to be by my case | 607,608 |
| | | Take out the next morning's medication | 610 |
| | | The evening medication, and put cling film over that | 612 |
| | | Will always have that in my pocket (re: GTN spray) | 973 |
| | | Whereas I'll clear everything else out of my pocket | 978 |
| Disturbance to routine | Distracted by activity | When all the family were here | 312 |
| | | The routine is a bit different (re: holiday) | 591 |
| | Change of timings | Timing dosages to that of the place we are going (re: time zone change) | 327 |
| | | Might be wider or less | 329 |

**Table 4.** Summarised themes and example interview quotes from Colin.

| **Superordinate theme** | **Subtheme** | **Mentioned by participant** | | | |
|---|---|---|---|---|---|
| | | **Gaye** | **Beki** | **Chris** | **Colin** |
| Comparison to others | Health conscious | • | • | | |
| | Unusual case | • | • | • | |
| | Parallel self | | | • | |
| | Compare to acquaintance | | | • | |
| | Compare to relatives | | | • | |

| | | | | | |
|---|---|---|---|---|---|
| | Chance affects health | | | | • |
| | Dislike of being labelled with diagnosis | | • | | |
| Knowledge | Medicines information | • | • | • | • |
| | Question cause | • | • | | |
| | Question medicines | • | • | | • |
| | Self-perception (medicines) | • | | • | |
| | Self-perception (fitness) | • | | | • |
| | Self-perception (medical) | | | • | • |
| | Cynical of care | | • | | |
| | Overcome medicine issue | • | | • | |
| | Seeking information | | • | | • |
| | Theoretical knowledge | | • | • | |
| | Practical knowledge | | | • | |
| | Follows professional advice | | • | | • |
| | Seeking superior healthcare | | | | • |
| | Paying for healthcare | | | | • |
| | Sharing knowledge | • | | | |
| | Strength in number | • | | | |
| Considering the future | Planning ahead | • | • | | |
| | Indefinite | | • | | |
| | Continuous future | | | | • |
| | Unknown future | • | • | | |
| Assimilation into lifestyle | Initial overwhelmed | • | | | • |
| | Concern for timing | | | | • |
| | Continue as usual | | | • | • |
| | Adapting to incorporate change | • | | • | |
| | Taking medicine is unremarkable | • | | • | • |
| | Unconcerned with adherence | | | • | • |
| | Child is priority | | • | | |

| | | | | | |
|---|---|---|---|---|---|
| | Concern for partner’s anxiety | | • | | |
| | Made own system | | | • | |
| | Concern for efficiency | | | • | |
| | Constructed relationship with regular medicines | | | • | |
| | Physical issue | • | | | |
| | Side effect tolerated | | • | | |
| | Side effect unacceptable | | • | | |
| | Location of medicine | | • | • | • |
| Disturbance to routine | Being out of the home | • | • | • | • |
| | Being on holiday | | | | • |
| | Distracted by activity | | • | • | • |
| | Changing of timings | | | | • |

**Table 5.** Summary of themes as mentioned by participant.

**Disturbance to routine.** All the participants discussed how a disturbance to their daily routine could result in their missing a dose of medication. Disturbances included being away from home, being on holiday, and distraction by another activity. In opposition to the previous theme, this was interpreted as a destabilisation of their habitual activity. They described “The routine is a bit different” and saying, “I went to bed and forgot that I’d not taken my pills”.

Being away from home was discussed as a reason by all participants. Gaye talked about going out and forgetting her evening dose of statin. Beki suggested that she might be out and forget to take a dose. Chris took his medicine box out with him to ensure he did not miss doses.

Colin’s wife gave him verbal reminders when away on holiday and he mentioned different time zones causing confusion.

Chris gave the example of being absorbed on the internet and so went to bed without taking the evening dose. Colin discussed missing doses when his family came to stay at his home.

## Discussion

This study has produced themes that add to our understanding of the experience of medicine taking following a myocardial infarction. The participants discussed medicine taking through four superordinate themes. Firstly, they *compared themselves* to others, often using this comparison to bolster their sense of wellbeing and provide optimism about themselves. Secondly, *knowledge* was important to them, to help them construct an understanding of their condition and its management. Thirdly, the participants all considered the *future* in some form, thinking of it as either a constant or an unknown concept. Fourthly, participants discussed ways that they fitted their *medicines into their lifestyle* each making unique adaptations to manage their individual medicines. A related theme to lifestyle, all participants discussed how *a change to their routine* adversely affected their medicine taking. The study offers an interpretivist perspective in an area weighted towards quantitative research. The themes provide patients' perspectives on medication, extending beyond the simple representation of adherence as either intentional or unintentional, helping therefore to give context to people's engagement with medication following a myocardial infarction. These themes could help guide practitioners to provide more patient-centred care in future health consultations. They also show that patients adapt medicine taking into their lives in various and unique ways and a tailored approach to support them would be appropriate.

Currently medicine adherence support is provided to this patient group at the primary healthcare level through GP services, where the main aim is to integrate hospital discharge and return to independent home living through a programme of cardiac rehabilitation. While social support and cardiac rehabilitation have been well documented to improve treatment outcomes and quality of life measures, it is also apparent that recovery is a complicated and multifactorial phenomenon. An important positioning paper by the European Association of Cardiovascular Prevention and Rehabilitation highlights the complex role that psychosocial-related factors play in both the genesis and recovery of CHD[27]. For example, psychosocial factors such as stress, anxiety and depression are implicated in the development of CHD, can be caused by CHD, and even reduced by CHD—the latter occurring when family rally round to increase social support following a diagnosis. The paper also discusses the complex ways that psychosocial factors influence cardiac outcomes and recovery, and how these factors can overlap and work in multiple directions, for example acting as barriers to lifestyle changes and treatment adherence. This complexity is in line with the themes untangled in this analysis, some of which conceptually overlap and affect one another, further emphasising the need for a patient-centred approach.

The theme of comparison to others and seeing one's own health protective behaviours as superior to others, could be construed as participants' way of evidencing their own health, maintaining control, and/or providing self-reassurance. This theme of comparison to others was also discussed in a narrative analysis of patients taking anticoagulant medicines to prevent stroke[28]. In that study, participants also constructed themselves as superior to others, evidencing their good intentions for example as good adherers while non-adherers were 'wasteful' or 'ungrateful'. Although a study of a different patient group, it agrees with this study that participants were keen to portray themselves as being healthy, adhering to medicines and positive lifestyle measures, and seeing others as having less favourable circumstances in terms of health. They found that missing doses was described as due to external circumstances of timing and location, and not linked to a personal trait. This supports the notion that participants are constructing an identity of positive health and higher morals than others to find comfort and gain control away from the tension of the uncertain. This finding highlights the need to consider the individual within group activities such as cardiac rehabilitation and social support groups, or when discussing benefits of treatment in terms of 'most patients'.

In the current study, the theme of knowledge is important because of its role in creating coherence whereby a clear model of treatment helps participants remove uncertainty and regain control of their self over their illness. Another study of the meaning of medication to patients also explored the role that knowledge and meaning play in helping patients understand and manage their medication[29]. That study found the medication experience to be a meaningful encounter, with positive or negative bodily effects, and an unremitting nature which could cause patients to question the need for it. The patients could even exert control over the medication through the expertise gained from taking it (e.g., take the medication only 'when required'). Parallels can be drawn with the current study under the themes of both knowledge and assimilation into lifestyle, as participants described their own experience of medication effects and side effects, sometimes questioning the need to take medication, and importantly, gaining control over the medication by simply taking it and not feeling it was unwarranted. This emphasis on meaning-making could be thought of as a learning process and therefore prompt practitioners to think about where a patient is in their learning journey when delivering patient-centred care.

Similarly, the theme of thinking about the future could add to a sense of coherence and continuity. It is noteworthy that medicines adherence is not often framed in relation to the concept of the future. In pharmacy, the professional focus is traditionally upon medical history and the future extends only as far as the patient's current valid prescription. The use of electronic transfer of record keeping, sharing, prescribing, and repeat batches of prescriptions, however, is potentially of benefit in terms of framing the future. This suggests more work could be done to investigate the impact of the current model of monthly prescriptions on patients' sense of their future and in turn their medication adherence.

Medicine-taking exists within the constructed life-world of the patient, affects and is affected by it. The theme of fitting into lifestyle, drawn out in this study, highlights the interconnectedness of medicines and patients' life-world. In this study patients had incorporated their medicines into their lives in unique and specific ways that were important to them and their beliefs. This adds further weight to the argument that reducing medicinetaking to 'cause and effect' is over-simplistic and of limited practical use. Against the good adherence work that the participants discussed, missing doses was attributed to being distracted, away from home, and timing issues. This is similar to the findings of a qualitative interview study of unintentional non-adherers taking medication for chronic c onditions[30], which found schedule change, life pressures, and location change to be reasons for adherence failure, suggesting that work to improve adherence should focus on these routine-related factors. The theme of 'change to routine' is arguably not disease-specific but associated with medication taking in chronic illness more generally. Routine is rooted in physicality, related to time, space and occupation, which could all be manipulated through behaviour change therapies in order to remove practical and perceived barriers to taking medicines[31]. However, this type of intervention might only be relevant where patients are unintentional nonadherers, who aim to be good adherers (compared to others), rather than for intentional non-adherers who have no intention of taking medicines to start with.

A rich, detailed description of the lived experience of medication taking was achieved by the devotion of time, care and attention to the analysis. By using a case study approach, the results cannot claim to be exhaustive as there is no endpoint at data saturation as found in some qualitative methodologies. However, the use of comparison between cases has elicited superordinate themes for further investigation. In line with the ideographic nature of an IPA study, the results are not generalisable to larger populations but could be cautiously broadened to establish how they fit amongst different groups. IPA requires a homogeneity of sample with respect to the phenomena under investigation, and this was achieved through purposive selection of participants as all having experience of taking medication to prevent further AMI. This sample was similar due to their locality to the South-East of England, similar socio-economic profile and using UK NHS services to provide their healthcare. The results are not intended to be generalisable to other AMI populations outside of this specific context, but this is not the intention of IPA, instead finding universal patterns within specific detailed accounts drawn out by the analysis and thematic grouping work towards cautious claims of transferability[32].

An equal gender mix was observed, but results were not de-aggregated, contrary to SAGER guidelines[33]. The rationale for this was the small participant number and ideography of an IPA methodology, where the focus is individual voice, and summary of detailed themes resonating through those voices, as opposed to a broader aggregation of themes.

The self-selection bias of participants may have affected the result of this study, as perhaps volunteers tend towards individuals with positive or more extreme experiences. The situational pressure of an interview may have contributed to the participants feeling obliged to satisfy the researcher's line of questioning and present themselves in the best possible light, in the same way that a medical consultation might do[34]. The method of analysis, IPA, is a close first-person study, and so the participant is interpreted as being truthful and without agenda. Future study to examine the performance and politics of the talk during the same interviews could be completed using discourse or conversation analysis as a more critical method.

The use of IPA fitted well with the research question and compliments the model of patient-centred care where empathy and understanding are valued. This study contributes to the discussion of methodology in phenomenological studies as the integration of existential categories was found to be useful in the organisation and analysis of the data. Other studies have found an integrated phenomenological approach to be beneficial to the production of their findings, such as using similar lifeworld categories[35], enactivism[36] and use of a revised grounded methodology[37].

This study has shown that whilst generalisations can be made, each patient's experience is unique and the meaning they associate to their behaviour and action is very personal. Therefore, the case study approach to developing medicine-taking interventions is a valid one. This is congruent with NICE recommendations for medicine adherence support to be patient-centred with interventions adapted to individuals[12], and future work to be directed towards this area. This patient-centredness could be practised in pharmacy by way of motivational interviewing as an aid to medicine adherence, which in the UK is not currently a standard practice within the NHS.

Whilst fulfilling the aim of describing the medicine-taking experience, the relationship to medication adherence, and more importantly, *non*-adherence is unclear. All the patients discussed rarely missing their doses, and so perhaps future studies could solely include the elusive volunteer group of non-adherent patients. This echoes the findings of the Cochrane review of adherence interventions[13], which concluded that more work ought to be completed with patients whose adherence is low.

## Conclusion

This study found the meaning of medicine-taking in this participant group was oriented towards reducing the unknown and reinforcing stability and cohesion in their lives. This finding, alongside the themes that the analysis generated could help practitioners assisting patients in their medicine-taking experience. The theme of *comparison to others* was found to confer a moral superiority to the self and offers comfort against uncertainty. The theme of *knowledge* and looking *towards the future* contributed to a participant's sense of coherence, again reducing anxiety of the unknown. *Assimilation into lifestyle* could be considered a modifiable learned behaviour, and *medication routines* could be strengthened by activity, location and timing interventions.

Meaning making was unique to individuals and so adherence interventions should be tailored to personal experiences in order to be more empathetic and therefore more impactful for an individual patient.

The methodology highlighted the importance of considering the phenomena of adherence as part of the whole life of an individual, as it is the entirety of a patient's world that imparts meaning to adherence. The ideographic approach of this study produced a rich dataset and aligns with a tailored intervention to improving adherence and with a patient-centred approach.

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Meta- analysis

# Medication- taking for secondary prevention of acute myocardial infarction: a thematic meta- synthesis of patient experiences

Hannah Piekarz, Catherine Langran, Amna Raza, Parastou Donyai

## ABSTRACT

## Key questions

### What is already known about this subject?

- Following an acute myocardial infarction, patients find it difficult to adhere to prescribed medication intended to improve their long-term health outcomes. An effective, practical adherence aid is yet to be developed, despite existing research into patients' experiences of medication- taking. These individual studies arguably lack external validity, which a meta-synthesis could help address.

### What does this study add?

- This study collates and synthesises qualitative research to elucidate similarities of themes across existing studies to give a rigorous, detailed understanding of medication-taking following an acute myocardial infarction.

### How might this impact on clinical practice?

- Improving understanding of medication-taking following an acute myocardial infarction allows researchers and practitioners to focus on developing more appropriate medication adherence interventions to assist patients' adherence and therefore improve their clinical outcomes.

**Objective** To collate existing qualitative research examining patients' medication-taking experiences in secondary prevention of acute myocardial infarction (AMI) and produce new knowledge, a systematic review and meta-synthesis of patient qualitative studies was conducted.

**Method** A systematic review found nine reports suitable for inclusion. Themes found by the report authors and report characteristic data were extracted. Reports were assessed for quality. A meta-synthesis using thematic coding and constant comparison method produced higher order themes, and these were used to construct a statement organised by theme using specific examples from the included studies.

**Results** All patients discussed their medication- taking in thematic categories of beliefs about medication and illness, personal ability and interpersonal factors. Themes differed between classes of medication and between patients, suggesting tailored interventions to medications and individual patients would be appropriate. Some themes overlapped with those discussed by the broader group of cardiovascular patients, but some themes were unique to this myocardial infarction patient group, again indicating that a tailored approach is appropriate for this patient group.

**Conclusion** The themes of beliefs about medication and illness, personal ability and interpersonal support provide tangible starting points for addressing adherence issues. The concept of medication- taking had unique elements within the post- AMI group of patients, and between classes of medication. While these themes were grouped into more generalised higher- order constructs, there were differences between patients within the themed group, indicating that themes are useful as a guide, but individual- level patient support is appropriate.

## INTRODUCTION

Following an acute myocardial infarction (AMI), medical treatment includes a life-long regime of taking five medications, risk factor control and lifestyle changes in order to prevent secondary myocardial infarction or further cardiac events.[1] However, medication adherence has been measured to be around 60% in this patient group,[2] showing a similar pattern across drug classes and falling as treatment duration continues.[3] Poor adherence leads to increased risk of mortality and shortened patient survival,[4] re-hospitalisation,[5] and incurs increased healthcare costs.[6]

A Cochrane Review of medication adherence interventions concluded that they are often complex and of little effect.[7] Within the larger group of cardiovascular secondary prevention patients, the use of short message service (SMS) texts, a combined pill and healthcare professional support have been found to be beneficial to adherence.[8] In the post- AMI patient group, interventions have assisted adherence to cardiac rehabilitation course completion, but not medication adherence,[9] while telephone or web-based prompts have a positive effect on adherence.[10] The patient perspective of this phenomena is under-researched, and validated theory does not exist, so current interventions to assist medication adherence are based on presumed principles. Qualitative methods are underused in cardiovascular research,[11] but could assist in creating a theoretical model and developing an appropriate intervention, the effectiveness of which could then be assessed using quantitative instruments.

This systematic review and meta-synthesis will provide a new account of this phenomena, by organising existing knowledge through comparison and thematic grouping. The aim is to investigate the existing qualitative research of medication-taking post- AMI and summarise themes across all studies, the differences and scope of our present knowledge. To date, this is the first systematic review of medication- taking in secondary prevention of AMI and makes an important contribution to understanding the issues faced by patients in order to develop appropriate interventions to assist their medication- taking.[12]

## METHODS

### Protocol

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses.[13] The PROSPERO, Cochrane Library and Joanna Briggs Institute registries were searched for existing work on 7 June 2021, and no systematic reviews of medication-taking post-AMI were found. The protocol for this study was not registered.

### Databases and search strategies

A search strategy was developed in collaboration with the academic department's subject librarian, using keywords within the fields of qualitative studies, medication- taking and AMI. Databases searched were PubMed, Scopus, PsycInfo, Web of Science and the Cochrane Library.

The PICOS tool defined the inclusion criteria for selecting items[14] (table 1). The titles and abstracts of the resulting papers were screened against the inclusion criteria for selection. The full text of the selected papers was read in detail before final selection.

Following final selection, a snowball search of each article's reference list and the 'cited by' function using PubMed was used to screen for other potentially relevant articles.

**Table 1** Study inclusion criteria based on PICOS tool

| Criteria |
|---|

| | |
|---|---|
| Population | Adults with diagnosis of myocardial infarction |
| Intervention | Taking medication to prevent further cardiac events |
| Comparison | Experience of taking medication |
| Outcome | (Not relevant here) |
| Study design | Qualitative data originating from patients, excluding survey or questionnaire studies |
| Other | Published in English, 2000–2021 |

## Study selection and data extraction

The search was conducted by HP and AR individually, and then compared and discussed. The search result data were recorded and organised using the EndNote web-based software.

## Reporting checklists of included studies

All included studies were critically considered against the consolidated criteria for reporting qualitative research (COREQ) 32- point reporting checklist[15] for qualitative studies. This checklist was used to examine how thoroughly the authors had reported the criteria of their studies. This assessment was carried out by HP and AR individually, then compared and discussed.

## Synthesis of results

The participant characteristic data and main themes reported by the original authors of each study were extracted and organised using Microsoft Word.

Thematic meta-synthesis was used to organise the findings of the search, chosen as the aim was to describe a specific concept.[16] According to this meta- synthesis method, the extracted themes were given line- by- line coding, compared with one another and grouped into common themes of a higher order and finally grouped under more encompassing super-ordinate categories [17] (table 2). Comparison tables of thematic groups were produced using Microsoft Word. The original papers were then used to add detail back into a prose statement organised according to the super- ordinate categories.

All data relevant to the study are included in this article or uploaded as online supplemental information 1.

## Patient and public involvement

Patients and the public were not directly involved in the design, analysis, or reporting of this research. This study is intended to be accessible to the public through Open Access publication and forms the foundation of future work by the authors to produce practical interventions that will be further researched through patient involvement and disseminated to wider patient communities.

# RESULTS

## Study selection

The database searches produced 368 citations, of which 43 duplicates were removed to leave 325 articles for title and abstract screening. This produced 23 eligible articles for full- text screening. Following this, eight articles were included in the review collection.

Snowball searching generated four further eligible articles, one proceeded into full-text review, and was subsequently added to the final review collection which now totalled nine (figure 1).

There were four super- ordinate thematic categories across the studies: medication beliefs, illness beliefs, personal and interpersonal factors.

**Table 2** Themes about medication- taking coded into higher order themes and super- ordinate categories

| Super- ordinate categories | Higher order themes | Themes |
|---|---|---|
| Beliefs about medication | Negative effects | Side effects[21,24,23] |
| | | Beliefs about consequences (negative outcomes)[19] |
| | | Medicine perceived as a barrier to recovery[22] |
| | Positive effects | Beliefs about consequences (positive outcomes)[19] |
| | Balancing pros and cons | Beliefs about consequences[20,18] |
| | | Necessity versus concerns[23] |
| | Preference for natural therapy | Use of ‘natural’ lifestyle measures in cholesterol lowering therapy discontinuers, not reported with clopidogrel[24] |
| Beliefs about illness | Believe to be in good health | Considered as not serious[21] |
| | | Believe health is good[21] |
| | Neutral health | Personal health feelings and beliefs[21] |
| | Believe to be in bad health | Worsening condition[21] |
| | Poor perception | Failure to recognise signs and symptoms of disease[21] |
| | Future threat | Reduced sense of threat of disease with cholesterol lowering therapy discontinuers, higher with clopidogrel[24] |
| | | Recurrent event[26] |

| | | |
|---|---|---|
| Personal adherence factors | Memory, attention, decision processes | Memory/attention/decision processes[192018] |
| | | Lack of continuity[21] |
| | | Reinforcement[19] |
| | | Forgetfulness[23] |
| | Self-regulation | Behavioural regulation[192018] |
| | | Self-medicating [21] |
| | | Unhealthy lifestyle choices[21] |
| | | Beliefs about capabilities[19] |
| | | Social influences (pre- existing beliefs)[19] |
| | | Identity[19] |
| | | Willpower[26] |
| | | A sense of competency[26] |
| | | Personal preferences[26] |
| | Poor perception | Missed general cues[21] |
| | | Inaccurate perception[21] |
| | | Prescription confusion[24] |
| | Determinism | Family history/fatalism[21] |
| | Emotion | Denial[21] |
| | | Mistrust[21] |
| | | Emotional toll[19] |
| | | Distrust of doctors[24] |
| | Economic | Economic burden[21] |
| | | Cost[24] |
| | | Living in areas of deprivation[23] |

Continued

### Medication beliefs

In summary, patients described positive or negative effects of medication, and balancing the need with their concerns over taking it. They took medication to remain healthy,[18] to not foreshorten their life[19] and to feel safe.[20] The side-effects of medication were described by patients as a bodily effect that needed to be dealt with in itself[20] and were not considered to be related to their cardiac issue. The side-effects caused pain, intruded into their lives and were a barrier to their health.[21] Similarly, the benefit of medication was unclear along with how it linked to their diagnosis.[22] They mentioned conflicting feelings,

**Table 2** Continued

| **Super-ordinate categories** | **Higher order themes** | **Themes** |
|---|---|---|
| Interpersonal adherence factors | General social | Social influence[2018]<br>Social/professional role and identity[2018] |
| | Communication | Lack of/poor communication[2125]<br>Lack of effective communication[21] |
| | Education | Inadequate patient educatio |
| | Knowledge | Lack of knowledge[2125]<br>Knowledge[1923]<br>Social influence (having knowledge)[19]<br>Cholesterol lowering therapy patient knowledgeable yet discontinued[24]<br>Clopidogrel less knowledge[24] |
| | Family | Lack of prompts from family and friends[21]<br>Family and relatives[26]<br>Family support[23] |
| | Healthcare professionals | Unaware of cardiac rehabilitation[21]<br>Healthcare providers[26]<br>Relying on health practitioner[23]<br>Cardiac rehabilitation[23] |

such as medication being an intrusion but also producing feelings of safety and were balancing the necessity versus their concerns over taking medication.[23] The concept of a future recurrence was a reason for medication-taking, [23] and medication was seen to be preventative.[23]

Patients conceptualised medication classes differently, giving dissimilar reasons for discontinuation between

**classes of medication, for example, those stopping clopidogrel were confused about the treatment duration, and those who discontinued cholesterol lowering medication talked about seeking more natural alternatives.[24] Also, patients pitched the side-effects of one medicine against**

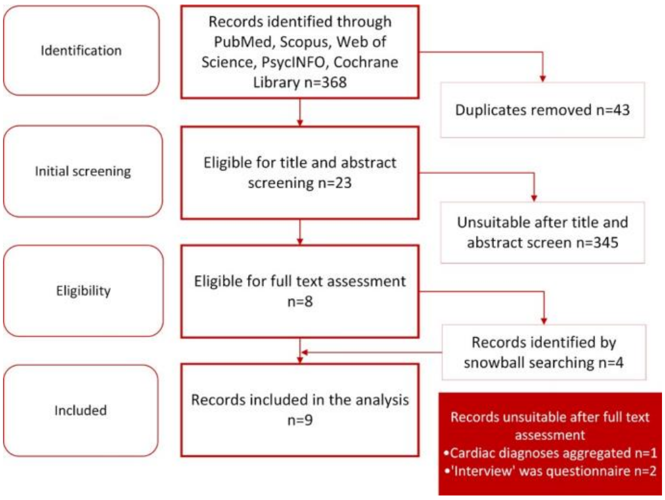

**Figure 1** PRISMA flowchart of the study selection process. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta- Analyses.

another, as those who discontinued taking clopidogrel described the side-effects of their cholesterol- lowering medication as painful and interfering with life.[24]

### Illness beliefs

Patients' perception of their own cardiac illness varied; some felt they were in good health,[21] or not serious,[21] some had neutral feelings,[24] or felt their condition was worsening.[21] They had differing beliefs about their susceptibility to a further myocardial infarction and were balancing feeling healthy against feeling ill.[23] When patients considered their illness to be more severe, they used a friend or family member as reference for comparison to their own illness.[24] They considered the possibility of a recurrent event, which could be prevented by taking medication.[23] Some patients felt depression following their cardiac event affected their medicine-taking. [19]

Some believed that their health was out of their personal control, discussing that genetics made it inevitable,[21] family history was outside their control,[19] or the will of God played a role.[23]

Several studies featured patients who discontinued one class of medication, finding similarities and differences in illness beliefs between patients. Similar across classes of drugs, patients discontinuing medication had an inaccurate self-perception, a worsening of their condition or denied their illness.[21] They showed a reluctance to engage in lifestyle changes, absolving that their previous positive health measures had not prevented their first AMI.[19] The severity of illness was perceived to be greater by patients who discontinued taking clopidogrel compared with those who discontinued cholesterol reducing medication.[24] Some patients who discontinued cholesterol- reducing medication believed they did not have a cholesterol issue, instead linking cholesterol- lowering medication to patients with high cholesterol, and not seeing the link to their own multi-faceted cardiac condition.[24]

### Personal adherence factors

Personal factors that affected medication-taking were linked to cognition; remembering and understanding their medication dosages. Themes that were elicited included memory,[19] memory, attention and decision processes,[18] continuity, reinforcement and forgetfulness.[23] Linked to this was poor perception,[21] patients missing the cues given,[21] being confused or receiving information inaccurately.[24] The use of a pill- box was given as an example of an adherence aid.[18]

The ability to self- regulate behaviour was discussed in several studies as a general theme,[18–20] and specifically described as patients talked of the discipline required to maintain their own medication,[21] their pre- existing beliefs as influences,[19] their belief in their own capability, as well as regulating their exercise and eating habits,[19] with reinforcement and consequences as an aid to adherence. Similarly, patients stated willpower, a sense of competency and personal preference as influencing their adherence.[23]

The emotional work required to take medication was described as a toll by patients,[19] some discussed the notion of denial of their condition,[21] as well as the negative feelings of mistrust[21] or distrust of the doctors providing their healthcare.[24]

Personal identity featured as patients mentioned the incongruity of seeing themselves as patients,[18] and comparison to other patients.[19] Some felt that medication was forced on them.[20] Economic poverty affected medication adherence, with the cost of medication a barrier,[21,24] as well as living in a deprived area.[23]

### Interpersonal adherence factors

Medication- taking was helped by healthcare professionals, who provided support,[23] reassurance[20] and communication.[18] Patients blamed poor communication by professionals and poor inter- professional communication as a reason for discontinuing clopidogrel.[25] The transition period following hospital discharge was a precarious time for their understanding[20] and receiving conflicting information added to confusion about treatment and illness severity. Also, clopidogrel non- adherent patients cited a lack of care continuity, lack of communication and inadequate education as factors.[21]

Patient's adherence was strengthened by having knowledge,[23] and lack of knowledge was stated as contributing to non-continuation of clopidogrel, [21] specifically knowledge about treatment duration and drug purpose.[25]

Support from family influenced medication- taking,[23 26] and a lack of prompt from family and friends featured for non- adherers.[21] Cardiac rehabilitation was stated as an influence on adherence,[23] and some non-adherers were unaware of the existence of cardiac rehabilitation programmes.[21]

## DISCUSSION

The aim of this study was to define the patient experience of taking medication following an AMI using thematic meta- synthesis of qualitative studies. In relation to medication adherence, patients discussed their illness beliefs, medication beliefs, personal and interpersonal factors.

Using meta- synthesis to collate and interpret the results, the claim for applicability to settings outside of the context each individual study is tentatively strengthened. Similarly, this meta- synthesis makes no claim of generalisability, but is intended to provide a resource to focus further work into theory development for testing in clinical practice.

We have highlighted the themes that patients discussed, but within these themes, patients produced a breadth of specific details, sometimes opposing, suggesting that adherence work should be done at an individual level for personalised assistance, in line with patient-centred medication adherence support advocated by the National Health Service (NHS) clinical guidance.[27]

The factors extracted in this review relate to the WHO dimensions of medical adherence; namely social/ economic- related, healthcare system-related, therapy- related, condition- related and patient- related factors that affect adherence.[28]

A notable finding is that taking medication reminds patients of their illness, and they attribute bodily effects to medication side-effects and not their original health issue. Patients' perception of illness varied, both in terms of severity compared with other patients and within themselves, and they balanced ideas of their healthiness with that of their illness.

Medication was seen as protective, and health- maintaining, with the concept of a future event a driver towards medication-taking. However, some patients balanced these beliefs with other more negative arguments that justified their choice to discontinue medication. This shows work is still needed to communicate positive health effects to patients, with dialogue needed to enable patients to voice their concerns. In other studies of medication adherence in chronic illness, patients are more adherent if their perceived need to take medication is greater than their concern over taking them.[26] The ambiguity of medication effects could be an issue for post-AMI patients who are asymptomatic or attributing symptoms as side-effects of medication. Practitioners should be aware of this issue when addressing patients' concerns about their medication.

The themes of knowledge, memory and social support from both family and professionals are important because they are tangible psychosocial factors that can be addressed using behaviour change techniques to assist patients.[29]

Scientific rigour and quality of results of this paper were strengthened by sourcing from peer-reviewed journals, and the COREQ checklist used as a valid and reliable measure of quality. No studies were deemed ineligible due to their quality, with scoring used as a guide for comparison, rather than an arbitrary cut- off.[30]

To show the coverage of studies included, it is worthwhile to highlight their epistemological positions.[29] Four studies were closest in theoretical paradigm to the aim of this study.[18 20 23 26] Two studies assessed the experience following the interventions of support via phone discussion and booklet respectively.[19 22] In the trio of related studies,[21 24 25] the context was patients who received coronary stent insertion as a result of their AMI. They also appear to have used the same cohort of patients, showing similar numbers and age range, perhaps limiting the breadth of results. Two studies used the Theoretical Domains Framework to organise the themes of their results,[18 19] and so were already organised into a higher order domain than the primary interpretations presented in all other studies.

**The studies reviewed were biased towards white male participants, with gender not reported, and from English- speaking developed nations with integral academic and healthcare systems. Only one study mentioned purposive sampling to balance ethnicity and socioeconomic status.[19]**

**There are two literature reviews that this research builds on. The first was a systematic review of all qualitative literature on medication adherence,[31] organised using Theoretical Domains Framework. This found three themes, medication-related burden, medication- related beliefs, which then fed into medication- related practices. There is a clear overlap with our study of medication- related beliefs and illness- related beliefs.**

**The second study of interest is a literature review of medication- taking behaviour for secondary prevention across patients of all types of coronary heart disease,[32] which concluded that medication-taking behaviour was a result of medication-related and disease- related beliefs, and related to clinician relationships, pre-existing health beliefs, socioeconomic and cultural environment, interaction with health systems and influence of partner and family. Again, there is overlap of the broad themes between this paper and ours. This second review included seven studies of AMI patients, four of which were selected in our review. A further five studies that we included were published later.**

**The authors of the study above found a number of unique themes including chronicity of illness,[32] a greater emphasis on fatalism, and patient confusion that they had been cured. Our study adds to this as we found the specific threat of a future event influenced patients' behaviour, and our study picked up depression as a feature of decisions which was absent in this second review. Of interest is one study of a Gujarati Hindu cohort[33] who discussed a significant belief in fate and the will of God, similar to that included in our study.[23]**

**This difference in findings supports the argument for tailoring interventions to a specific AMI diagnosis to help guide thematic concepts and predict individual issues. Additionally, acknowledgement of similar experiences assists empathy and developing professional trust.**

**The authors of this review have a study in publication that is also relevant.[34] Our study found that patients discussed similar personal factors to those identified in this paper, for example, the assimilation of medication into their lifestyle, knowledge in general and disruption to routine. Under the theme of illness beliefs, we found that patients considered the future, compared themselves to others, and were keen to distinguish themselves from the notion of a 'typical' AMI patient.**

## CONCLUSION

**This systematic review and meta- synthesis of medication- taking to prevent further AMI has found that patients expressed varied beliefs relating to medication and their illness. Most importantly, patients differed in the concept of their own health and how it related to their cardiac illness, and the effect of taking medication on their bodies and how this influenced their health. They were supported by family and professional help, and their own knowledge, memory and capability assisted their medication- taking.**

**These findings indicate that intervention work should be done at an individual level, due to personal variation in beliefs, and also at drug class level, as patients conceptualised drug classes differently.**

**Healthcare professionals can use beliefs about medication and illness as starting points for intervention work, and be observant during everyday practice that patient knowledge, communication and continuity of care are important to help patients with medication-taking following an AMI.**

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