

*The experiences of the community
pharmacy team in supporting people with
dementia and family carers with
medication management during the
COVID-19 pandemic*

Article

Accepted Version

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Shalhoub, R. and Sridharan, B. K. (2021) The experiences of
the community pharmacy team in supporting people with
dementia and family carers with medication management
during the COVID-19 pandemic. *Research in Social and
Administrative Pharmacy*, 17 (1). pp. 1825-1831. ISSN 1934-
8150 doi: 10.1016/j.sapharm.2020.10.005 Available at
<https://centaur.reading.ac.uk/93456/>

It is advisable to refer to the publisher's version if you intend to cite from the
work. See [Guidance on citing](#).

To link to this article DOI: <http://dx.doi.org/10.1016/j.sapharm.2020.10.005>

Publisher: Elsevier

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Title

The experiences of the community pharmacy team in supporting people with dementia and family carers with medication management during the COVID-19 pandemic.

Abstract

Background: The novel coronavirus COVID-19 pandemic has changed the lives of people across the globe in significant and long-lasting ways. People with dementia were significantly and disproportionately affected at the height of the pandemic in England.

Community pharmacies in England continued to operate during the pandemic but had to adjust the way they provided key healthcare services. The impact of these changes on the provision of medication services to people with dementia is underexplored.

Objective: To explore the experiences of the community pharmacy team in supporting people with dementia and family carers manage medications during the COVID-19 pandemic.

Methods: An interpretivist/constructivist research paradigm was used; semi-structured one-to-one telephone interviews were conducted with any member of the community pharmacy team who had been involved in providing medication services to people with dementia in England before and during the COVID-19 pandemic. Recruitment took place between July and August 2020. Interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis.

Results: Fourteen participants were interviewed with equal numbers of qualified pharmacists and non-pharmacist staff. Participants were in their role for an average of 4.5 years. The analysis of interviews generated three themes: 1) key interactions curtailed due to COVID-19 restrictions, 2) utilising resources within and outside of the pharmacy to provide tailored services for people with dementia, and 3) the interplay between professional duty and personal values underpinned decisions to provide medication services.

Conclusions: The study provided a unique and important first insights to our understanding of how the community pharmacy team in England supported people with dementia and their family carers during the COVID-19 pandemic. These insights provide opportunities for reflection by individuals, healthcare teams, healthcare organisations, policy makers and the

public, in an international context, to enable long-term planning, investment and implementation of strategies beyond the current pandemic.

Keywords

Community pharmacy, dementia, medication management, COVID-19

Introduction

The novel coronavirus COVID-19 pandemic has changed and is continuing to change the lives of people across the globe in significant and long-lasting ways. At the time of writing, around 35 million cases of COVID-19 infections have been reported and more than 1 million people have died because of COVID-19, worldwide¹. It has been ten-months since the novel coronavirus was first identified in Wuhan, China and seven-months since the World Health Organisation (WHO) declared a global pandemic² – the world is still learning about this novel virus and the end of the pandemic is not yet in sight with a resurgence in some countries³. Governments and healthcare systems across the world are responding to the novel COVID-19 pandemic in different ways.

In the United Kingdom (UK), the rate of infection was increasing between 5-9% per day at the time of writing⁴. The focus of the English government continues to be on reducing virus transmission. At the height of the COVID-19 pandemic in England, restrictions such as ‘shielding’ (not leaving their homes and minimise contact with others) clinically extremely vulnerable people, social distancing (maintaining two metres distance between individuals) and self-isolation were in place. These restrictions affected the general population and some vulnerable groups such as people with dementia were significantly and disproportionately affected⁵. Dementia was the most common pre-existing condition for COVID-19 deaths in England and Wales accounting for 25.6% of deaths⁶. More than 90% of people with dementia have at least one other health condition⁷ and are at higher risk from COVID-19. This meant that many people with dementia, of which around 61% live at home⁸ and 1/3 live alone⁹, were house bound. For many people with dementia, medications are a key part of daily living. Managing medications is complex and multifaceted¹⁰⁻¹¹ and can lead to medication errors and medication-related hospital admissions¹². Therefore, it is important to ensure that the system of managing medications is robust and fit for purpose. During the pandemic, however, many people with dementia were not able to access medications as they would normally.

Community pharmacists in the UK continued to operate during the pandemic. With around 1.6 million visits to community pharmacies per day in England alone¹³, they are one of the

most easily accessible healthcare professionals providing a key health service to the population. Spaces within community pharmacies enables multiple functions and complex interactions to take place with the public, providing opportunities to support the health and wellbeing needs of the general population. However, during the pandemic, community pharmacies had to adjust the way they used such spaces and how they provided key healthcare services. The impact of these changes on the provision of medication services to vulnerable patient groups such as people with dementia was unknown.

Aim

To explore the experiences of the community pharmacy team in supporting people with dementia and family carers, specific to medication management during the COVID-19 pandemic.

Methods

This qualitative study is reported using COREQ¹⁴.

Research team and reflexivity

The research team consisted of two undergraduate female Master of Pharmacy students (RS, BK) and a female academic pharmacist with a doctorate and experience of qualitative research methodology (RL). RS was trained by RL and conducted all the interviews. BS was trained by RL and undertook the analysis of the interviews.

Participant selection

Purposive sampling was used to recruit participants via key contacts within RL's existing networks using email, social media (Twitter and Facebook) and word of mouth. RL emailed key contacts with the study invitation letter, participant information sheet and consent form. They then sent out information about the study via email to their own networks. The **inclusion criteria** were any member of the community pharmacy team who were over the age of 18 years old and had been involved in providing medication services to people with dementia in England before and during the COVID-19 pandemic. Recruitment took place in

July and August 2020 until a maximum of 15 participants had been interviewed. The focus was on the 'depth/richness' of data collected rather than the breadth (e.g. existence of new information). Informed consent was given prior to interviews.

Study design

An interpretivist/constructivist paradigm underpinned the design and conduct of this study¹⁵; people who work in the community pharmacy have different experiences of supporting people with dementia/carers. Phenomenology as a methodology was used to explore and understand unique participants' experiences using semi-structured one-to-one interviews. Researchers actively encouraged discussions emphasising the uniqueness of participants' experiences and constructed meaning from interview data shaped by their own personal perspectives.

Setting

Interviews were conducted over the telephone by a single researcher (RS) at a time that suited the participant.

Data collection

One-off one-to-one semi-structured interviews were conducted over the telephone. Interviews explored 1. The range of services provided to people with dementia/family carers and the general aim of these and, 2. Two examples of service provision (one pre- and one during the COVID-19 pandemic): the general circumstances leading up to the example given (individual, team, ward and organisational levels), action taken (how, why, when, where), facilitators and barriers to performing task, informed by the Critical Incident Technique¹⁶. Demographic data such as age, gender, years in practice/role, type and location of practice were also collected to describe the sample of participants. The interview schedule was piloted several times within the research team and changes made to the interview schedule. See Box 1 for the final version of the interview schedule. All interviews were audio-recorded with consent from participants and then transcribed verbatim by BK onto Microsoft Word documents. Every transcript was checked against the corresponding audio-recording for accuracy. Any identifying information was removed at the point of transcription.

Box 1: Interview schedule

General demographic questions

- Can I ask what your role is in your pharmacy? Tell me a little about that.
- How long have you been in your current role?
- How would you describe the environment in your pharmacy is like on a daily basis? (before and during the pandemic)

Range of services and general aim

- On average, in a week, how many people with dementia or their carers do you meet? (before and during the pandemic)
- We are interested in the types of medication services that you provide for people with dementia, living in their own home. Can you describe to me these types of services?

Example before COVID-19

I am very interested to find out what life was like before the pandemic, in terms of the medication services that you provided for people with dementia.

- Can you go back to before the pandemic happened and recall a specific example of a time you provided a medicine service for a person with dementia. Talk to me about the experience in as much detail as you can.

Prompts: regular basis, when needed, how the service was developed, what helps, teamwork, feedback regarding service

Example during COVID-19

Now using this same exact service, were you able to provide this service or not since the pandemic started?

- If they haven't been able to provide the service,

Prompts: how do you feel about not being able to do so? What do you think needed to happen for you to be able to do it?

- If they continued to be able to provide the service,

Prompts: what changed from the last time you provided it? If anything? What helped you provide this service? How has the team around you contributed to it? Also, here, any feedback or way of monitoring?

Generally, what changes (if any) have you incorporated into the workplace for people with dementia during the pandemic?

What else could have been done differently? What do you think might/would help you do better in providing these services?

If a second wave was to hit, do you think you will be prepared for it? Are there any preparations made for you to do your job safely?

Is there anything else you would like to add to what we have just discussed?

Data analysis

Interviews were analysed using inductive thematic analysis¹⁷. Guided extensively by RL, an experienced qualitative researcher, BK analysed the interview data. BK familiarised herself with the interview data through the transcribing of the audio-recordings, reading and re-reading the interview transcripts. Using NVivo 12¹⁸, BK then undertook line-by-line coding of each interview transcript. Initial themes were generated and then reviewed against the interview dataset. Following further refinement of themes, BK developed a detailed analysis of each theme. The analysis process was iterative and multiple discussions were held between BK and RL at each stage of the analysis to guide the analysis process, not to achieve consensus on the interpretation of interview data.

Results

Participant demographics

A total of 14 participants consented and took part in the interview study. Interviews took place between July and August 2020. Due to the way in which recruitment was conducted, it was not possible to ascertain the number of people whom the study invitation may have reached. Recruitment stopped when there was sufficient depth/richness to the data. Table 1 shows the demographic data of participants. Most participants were female (n=10, 71%) and half were under 30-years old. There were equal numbers of qualified pharmacists and non-pharmacist staff who took part in the study. Half of the participants worked in independent pharmacies. Pharmacies where participants worked were mostly concentrated in the South East of England (see Figure 1). Participants were in their current role between 4 months and 13 years (mean = 4.5 years). Interviews with participants lasted between 18 and 38 minutes (mean = 29 minutes).

Table 1 Demographic data of participants (n=14)

Gender	
Male	4 (28.6%)
Female	10 (71.4%)
Age	
18-29 years	7 (50%)

30-39 years	4 (28.6%)
40-49 years	3 (21.4%)
Role in the pharmacy	
Pharmacy dispenser	5 (35.7%)
Pharmacy technician	1 (7.1%)
Pre-registration pharmacist	1 (7.1%)
Pharmacist	7 * (50.0%)
Time in post	
0 to 1 year	5 (35.7%)
2-5 years	5 (35.7%)
6-13 years	4 (28.6%)
Ownership of pharmacy	
Independent	7 (50.0%)
Part of a chain	6 (43.0%)
Independent and part of a chain	1 (7.0%)

*5 store pharmacist/pharmacist manager, 2 long-term locum pharmacist



Figure 1: Location of the pharmacy where participants' worked.

Medication services provided for people with dementia

Before the COVID-19 pandemic, the range of medication services provided for people with dementia included compliance aids (for example, dosette boxes, blister packs and monitored dosage systems), medication administration records (a document used to record the administration/taking of medication), medication home delivery services, Medicines Use Reviews (structured medication reviews with patients taking multiple medications), New Medicines Services (support with taking a new medication), repeat dispensing service (dispense repeat dispensing prescriptions issued by a General Practitioner), minor ailment scheme (advice and treatment for some common illnesses) and the flu vaccination service. Most of these services are funded by the National Health Service (NHS) whilst others such as medication administration records and medication home delivery services are not. Pharmacy teams prioritised the provision of medication services that they considered to be

essential during the pandemic such as compliance aids, medication administration records and medication home delivery services. Services that typically required face-to-face contact such as the Medicines Use Reviews and New Medicines Services were paused.

Qualitative findings

The analysis of interviews generated three themes: 1) key interactions curtailed due to COVID-19 restrictions, 2) utilising resources within and outside of the pharmacy to provide tailored services for people with dementia, and 3) interplay between professional duty and personal values underpinned decisions to provide medication services.

Key interactions curtailed due to COVID-19 restrictions

The COVID-19 restrictions relevant to the study context included the use of personal protective equipment (PPE), social distancing measures (2 metres between individuals) and the 'shielding' of vulnerable individuals (a measure to protect people at high risk from COVID-19 by staying at home and avoiding all face-to-face contact. This ended on the 1st August 2020 in England). The critical aspect of social interaction for people with dementia was not possible. People with dementia who wanted to collect their medication were unable to do so because they were 'shielding'. Some pharmacies spent time finding out the personal circumstances of people with dementia, whether they had someone who could collect medications on their behalf. For many, pharmacies started delivering medications to the people's homes. The reduction in face-to-face contact also meant that pharmacy teams were unable to have the same level of interaction with people with dementia with regards to their medication. Maintaining independence and autonomy over medications were challenged.

"...even the ones that wanted to collect but that was their independence and they quite like coming into the shop seeing us, they had to shield." Participant 10

“The patients that we did see with dementia [before the pandemic], we don’t see them at all. The communication itself with them is a lot harder. We tend to see their family more than the patient themselves.” Participant 1

For people with dementia who usually have their medications delivered, the social distancing measures also impacted negatively on the interaction that they had with the pharmacy delivery driver. This posed challenges in identifying important cues from people with dementia. Pharmacy teams were faced with difficult decisions, balancing the COVID-19 restrictions and providing high quality care.

“...you’re now having to arrange deliveries in such a way that it’s observing social distance so where our delivery driver would typically have, know quite a lot of the patients because of the interactions she has with them, that has stopped purely because now having to observe the 2 meters. There’s minimal kind of communication so you’re not getting as much information indirectly from the patients during the interactions. So, I think that’s definitely a small part of it but it’s overlooked because you quite often get a lot of information from how patients are doing in that way.” Participant 8

Utilising resources within and outside of the pharmacy to provide tailored services for people with dementia

The importance and value of teamwork was amplified during the time of the pandemic. Each pharmacy team member had specific skillsets; these were acknowledged even before the pandemic and used collectively to benefit the pharmacy team and patients. The teams’ previous experiences with people with dementia meant that they were confident in providing services both prior to, during and if there was a resurgence of the pandemic.

“So, I’d say it’s probably a build-up of experience and understanding systems that are available to us. So, understanding that you know, there are dosette boxes, there are MAR charts, there are patient contacts, Dementia Friends. I think it’s just a build-up

of information and build-up of experience. I think like 5 years ago, I probably wouldn't have dealt with it so well, if I'm honest." Participant 12

Pharmacy team members worked together to ensure that patients received their medication; many worked overtime to clear prescription back-logs and to ensure that staff on the next day were able to focus on the day's work.

"...we stayed until about 2 am, trying to catch up from a back log because at one point they were, I think we were like five days behind on prescriptions. So, me and my senior dispenser there stayed until 2 am trying to catch up some of this crazy back log and hopefully set the weekend staff up with, you know, something that was a bit more manageable." Participant 5

Pharmacies made difficult trade-offs during the pandemic. Not all services continued during the pandemic. For example, pharmacies were asked not to continue to provide medication in compliance aids; some were able to continue with the service whilst others did not.

"...we were given the alternative from NHS England that we could, rather than do the dosette tray, we could just send the MAR chart out with the boxes in 28, you know in their normal dispensing pack. But we, myself and my dispenser, made a decision that we would carry on supplying the dosette boxes. Their thinking was, if we all got ill with COVID, the dosette boxes are quite time consuming and it was to reduce the workload but we felt, especially patients with dementia, they got used to that system, and then to go and change it, wouldn't be very fair on them and cause anxiety. So, we decided to keep it as it was, so that...simple as it could be for those dementia patients." Participant 6

“...doing the trays, the dosette boxes [compliance aids] and we did have to cut that out unfortunately. It was part of company protocol. Just quite unfeasible.”

Participant 14

Pharmacies drew on external help to provide services to people with dementia. NHS England/Improvement provided crucial funding to enable pharmacies to provide home medication delivery services, that would otherwise be financially unsustainable. Pharmacies also accessed support from volunteers that were part of the NHS Volunteer Responders programme that was set up to support the NHS and social care sector during the pandemic. These volunteers delivered medication to people’s homes.

“That [funding] also allowed us to extend the service to I suppose to those patients who we wouldn’t have delivered for. Because we were having to scale back on deliveries anyway prior to, so that only picked up as a result of the funding that went into pharmacies for this pandemic specifically.” Participant 8

“...it was just incredibly crazy you know, everybody just needed their prescriptions delivered. So, it was very hard but we had to rely on extra support from these NHS volunteers, otherwise we really would have struggled but we did it in the end.”

Participant 9

Interplay between professional duty and personal values underpinned decisions to provide medication services.

Although many pharmacies are remunerated under the Pharmacy Quality Scheme when they complete the Dementia Friendly Environment Checklist and undertake training to become Dementia Friends, many focused on building relationships with people with dementia and their family. It is the rapport, trust and understanding of the person’s circumstances that underpinned their decision-making in the provision of medication services before and during the pandemic.

“...we flag it up if someone’s got dementia so we know like if they’re ringing us or that we can help them. So, we know our customers that need more help than others, so like on a personal basis so I guess that’s how we try and help them.” Participant 2

Pharmacy staff were willing to meet the needs of individuals even in very unusual situations, at the pharmacy/their own expense. The interplay between professional duties/role and personal values appears to be the catalyst for decision-making relating to the provision medication services.

“Obviously, I’m sure that you’re aware that that’s not possible and that we couldn’t source that [five-compartment compliance aid] from anywhere. So, we have to make the four-compartment tray, the usual one and then we have to cut up an extra one and cellotape it on. It’s because that that patient is so into their disease progression that they need that extra one, so we make a five one. Five-compartment one ourselves.” Participant 4

“There was one in particular and she [person with dementia] lives in sheltered accommodation, but she doesn’t have any family, and one of medicine counter assistant took around her prescription for her, because she only lives around like the corner to walk there and it came down on a Friday when we didn’t have a driver” Participant 7

Discussion

This study provided a unique and possibly the first view on the experiences of the community pharmacy team in providing medication services to people with dementia and their informal carers prior to and during the COVID-19 pandemic, within an English context. Our principal findings were that key face-to-face interactions with people with dementia stopped during the COVID-19 restrictions but pharmacy teams drew extensively from internal (pharmacy/personal) and external (government) resources and negotiated

professional decision-making and personal values to provide essential medication services to people with dementia.

In the early stages of the COVID-19 pandemic in England, face-to-face interactions were restricted because many people with dementia were 'shielding', following government guidelines. Community pharmacy teams were able to adapt very quickly to the immediate needs of people with dementia, for example, in providing medication home delivery services, with additional funding from NHS England. Other key aspects of medication management for people with dementia, however, must not be neglected during a pandemic. Key aspects such as discussions about concerns relating to medications and regular monitoring to ensure medications are still being used appropriately are important not only to ensure medication safety but also to maintain/develop trust between the community pharmacy team and the person with dementia/informal carer. Alternative methods to communicating face-to-face such as telephone and video-consultations could be viable options¹⁹⁻²² to complement and not replace face-to-face communication. The needs of the pharmacy, pharmacy team, people with dementia and their informal carers, however, will need to be considered before adoption. How would the person with dementia respond to speaking on the telephone or video-call? Are video-conferencing facilities available, and if they are, what are the training needs for the pharmacy team and people with dementia/informal carers who may not routinely use this form of technology. These are not insurmountable issues but will require careful consideration in close collaboration with people with dementia and their informal carers and additional funding. It is important to ensure that the needs and voices of people with dementia and their carers are heard and addressed²³ to ensure that safe and effective provision of services. Working with third sector organisations that advocates for people with dementia for example, the Alzheimer's Society in the UK and Alzheimer's Association in the US, can facilitate effective partnerships between patient groups and care providers.

Teamwork was key in enabling participants to provide crucial medication services to people with dementia, and consistent with Salas et al.'s²⁴ model of five key dimensions of effective teams. For example, team leadership that extends beyond coordination and planning, and includes development of the team in utilising the complementary skillsets, knowledge and

experience of the pharmacy team was evident. Participants also described teams that were sensitive to the needs and strengths of individual team members culminating in proactive support of each other. The adaptive capacity of participants and their teams, for example, in switching to home delivery, providing a five-compartment dosette box to mention a couple, was important to ensure that people with dementia continued to receive support with their medication. It was also clear that participants worked as a team and these teams shared the same goals of wanting to care for people with dementia as best they can given the COVID-19 restrictions. There was mutual trust and respect for members of the team. Effective teamwork has been associated with safe and effective care²⁵⁻²⁸ and especially important when caring for vulnerable groups of patients such as people with dementia who may require additional help. Developing effective teams is not easy and requires investment and interventions targeted at individual, team and organisational levels²⁹. With increasing efforts to work in partnership/close collaboration with people with dementia and carers in research³⁰, it is prudent to consider if, how and to what extent the 'team' in a community pharmacy setting could extend beyond pharmacy staff to include people with dementia and carers, and other healthcare professionals within an inter-professional healthcare context.

Implications for practice and future research

COVID-19 has highlighted potential areas for long-term planning and investment necessary for resilient provision of medication services for people with dementia within the community pharmacy setting. Firstly, community pharmacies can explore opportunities to work closely with people with dementia/carers to design services that are safe and effective. Working with local patient groups is a good starting point. Secondly, the use of technology in supplementing face-to-face interactions warrants further consideration and research. A Human Factors and Ergonomics (HFE) design approach that emphasises a user-centred, whole systems view is highly recommended in analysing, designing, and implementing technological solutions³¹. The HFE approach emphasises meaningful collaboration with people with dementia/carers as users of services. Participants emphasised the importance of teamwork and there are also opportunities for HFE experts to work with community pharmacy teams, people with dementia and carer and the wider inter-professional healthcare professional teams to enhance and/or develop teamwork

focusing on non-technical skills (interpersonal skills including cognitive and social skills)³². Finally, it is important to have a long-term view when developing and refining medication services rather than introducing short-term solutions that may not be sustainable and resilient over time. The concept of Resilient HealthCare (RHC)³³ that is gaining traction amongst safety and clinical researchers could be explored and applied in this setting. There are increasing efforts to study RHC and identify ways to develop and enhance RHC such as effective team relationships, trade-offs and 'resilience' training of health care professionals, that can be drawn upon³⁴.

Strengths and limitations

Empirical research on the experiences of the community pharmacy team in providing medication services to people with dementia and their carers in England during the COVID-19 pandemic is scarce. This original study provided new insight to our understanding of their experiences during a significant time-point during the pandemic. During the time of writing, there is a resurgence of COVID-19 in England and some countries worldwide. The work presented in this study will be of relevance to countries across the world during and beyond COVID-19, where community pharmacies play an important role in providing crucial medication services to people with dementia. For example, the involvement of people with dementia and carers in the design and provision of medication services, careful consideration of the use of technology to enable rather than hinder and realising the benefits of effective teamwork in better patient outcomes.

An interpretivist/constructivist paradigm was used to understand the experiences of the community pharmacy team and as such, the findings were shaped by the researcher's personal experiences. A different research paradigm such as grounded theory may derive different meanings from the interview data. Although the student researchers were new to qualitative research, they were guided extensively by the research supervisor at each stage of the research process. Participants were an opportunistic sample and willing to discuss their experiences openly and in-depth. Therefore, there may be a tendency and bias towards expressing positive experiences. Participants recalled their personal experiences providing medication services to people with dementia prior to and during the pandemic.

Their recall of specific examples of medication provision, guided by our interview questions, may be subject to recall bias and may not accurately reflect what happened. Nevertheless, the study aimed to construct a view of the experiences of the community pharmacy team, and not individual experiences.

Conclusion

The study provided a unique and important first insights to our understanding of how the community pharmacy team in England respond to the COVID-19 pandemic, specific to the provision of medication services to people with dementia and their informal carers. The implications of the study extend beyond the current pandemic and the English context to provide opportunities for reflection by individuals, healthcare teams, healthcare organisations, policy makers and the public, to enable long-term planning, investment and implementation of strategies.

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CRedit author statement

Rosemary Lim: conceptualisation, methodology, writing-original draft preparation, supervision, funding acquisition. **Reem Shalhoub:** investigation, writing – review and editing. **Barati Keshine Sridharan:** formal analysis, writing – review and editing.

Declarations of interest

None.

Funding

The study was supported by the Undergraduate Research Opportunities Programme, University of Reading and Brian Revell Memorial Fund.

Acknowledgements

We would like to thank all the community pharmacy staff members for taking time to speak with us.