

A qualitative study exploring medication management in people with dementia living in the community and the potential role of the community pharmacist

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1. Context

It is estimated that dementia has a global prevalence of 47.5 million individuals (1). In the UK, 800,000 people live with dementia – this figure is expected to double by 2040 as the population ages, reflecting global predictions (2-4). Dementia has been identified as the main disease state which increases the likelihood of risk factors for adverse drug reactions due to factors including a lack of pharmacy input, drug interactions, comorbidity and polypharmacy (5,6). Moreover, the cognitive impairment seen in dementia may result in a lack of capacity to safely and effectively self-administer medication, (7,8) consequently increasing the risk of medication errors (9). Despite people with dementia (PwD) being particularly susceptible to adverse drug events, they are commonly prescribed complex medication regimes and on average may receive five different medicines (5,9,10).

With increasing cognitive impairment, medication management particularly with complex regimens is often shifted from the personal responsibility of the PwD to the control of formal (paid) or informal (family) carers (9,11-14). Informal carers often have a key role in ensuring safe and effective medication use as they may conduct up to 10 medication management activities every day, including awareness of and managing side-effects, and decisions to administer medication (15,16). Unlike health professionals, family and friends who are informal carers, may not receive any training or have access to evidence-based information to appropriately support medication management (15,17). In fact, informal carers may not feel equipped for such an augmented role which they can find burdensome and stressful, this can reduce informal carer's and PwD's quality of life and precipitate collapse in the domestic care arrangement (13,14,16,18-21).

Various groups of health and social care professionals (HSCP) may support informal carers with managing the medication. Indeed, without the support and collaboration of health professionals involved, informal carers may struggle to adequately support medication management especially of complex regimes (7). However, healthcare professionals lack time and may not be aware of the issues faced by informal carers and PwD (22,23). Furthermore, the information about medication regimens, provided by healthcare professionals can be too complex to be understood by a lay person and sometimes is not directly communicated to the informal carer due to the perceived confidentiality issues (15,17,22).

The role of community pharmacists is changing from being focused on the supply of medicines to providing clinical services (24,25). There is clear potential to expand the role of community pharmacists in medication management in PwD (26-28). The change in role is supported by both UK government policy and pharmacy professional bodies (28-30). The available literature argues that community pharmacy services available for PwD are poorly developed (6) and the need for further research exploring the role of community pharmacists optimising medication management in PwD has already been identified (31). It is important then to explore the perspectives of the key stakeholders to understand how community pharmacists can support PwD living in the community with medication management.

2. Aims and objectives

2.1 Aim

To understand the role of community pharmacists in supporting people with dementia, dwelling in the community, to manage their medication and the key challenges in the population.

2.2 Objectives

To describe and understand the key problems and challenges, in relation to medication issues, experienced by people with dementia dwelling in the community (living at home) and their informal carers

To explore how medication management could be improved for people with dementia dwelling in the community

To use our findings to describe key aspects of a new role for community pharmacy in medication optimisation in dementia

3. Approach and Methods

3.1. Study design

This report used a qualitative approach with data collection being undertaken by trained researchers [AH, TM, LA]. The study received ethical approval from Aston University Research Ethics Committee.

Data triangulation from three studies (a meta-synthesis, qualitative framework analysis and an Interpretative Phenomenological Analysis) were used to provide a valid and reliable understanding of the objective of this report from different perspectives. Before starting further qualitative work a meta-synthesis was conducted (32). The meta-synthesis was conducted in order to explore (and appraise) published literature investigating medication management in PwD living at home; the effect managing the medication of care-recipients has on informal carers of PwD and the role healthcare professionals have in supporting PwD and their informal carers manage medication. Investigating several studies exploring the same topic by means of a meta-synthesis, enabled the authors to identify different approaches and interpretations of dementia, medication management and the role of community pharmacists. This background investigation informed the interview schedule for the exploratory work and it allowed the results from the interviews to be positioned in the wider context.

3.2. Meta-synthesis

A mixed studies meta-synthesis was conducted (32). Three databases were searched (Web of Knowledge, PubMed and Cochrane Library) for studies set in the community (in participants' homes) exploring, measuring or evaluating medication management in PwD. These databases were searched in November 2014 with restrictions to English language papers and post 1999 papers. Searches were updated in April 2015 and January 2016. Data from included studies were synthesised using convergent synthesis methods and analysed thematically (33).

3.2.1. Inclusion criteria

Studies were included if:

- They were set in the community, in the homes of people with dementia;
- They measured or evaluated medication management;
- They used any method using a quantitative and/or qualitative approach including randomised controlled trials and other interventional studies.

3.3. Exploratory research, sampling and recruitment

In order to conduct further exploratory research, participants were recruited from the Alzheimer's society, Dementia UK, local GP surgeries, professionals networks, and local dementia support

groups (including a support group for people with dementia in the black and minority ethnic [BME] community in Yorkshire). The organisations were contacted by LA and IM via telephone and email, and asked about their willingness to collaborate in advertising the study. Also, they were provided with information and details of the research, what taking part in this study would involve and the criteria individuals had to meet to be eligible to participate. Recruitment was also conducted through snowball effect as contacts were requested to suggest other PwD, informal carers and HSCP who might be willing to take part in this study. After their approval to collaborate in advertising this study, the contact details of LA and IM were provided and potential participants were free to contact IM and LA via email or phone to express their interest in participating. An email was then sent to all potential participants, who expressed an interest in the study, with an information sheet with details of the study and a consent form followed by a request for their availability in case they agreed in taking part. A total of 32 participants were interviewed for this study. Details of the participants and the interview schedules are available in the appendices section.

3.3.1. Qualitative framework analysis

The final sample for this study comprised of 32 participants (eleven informal carers; five PwD; sixteen Health or Social Care Professionals [HSCP]. From the sixteen HSCP, four were general practitioners, five were nurses [practice and district nurses], three were paid carers and four were community pharmacists).

A qualitative framework analysis was undertaken in order to explore the experiences and perspectives of PwD, informal carers and HSCP (including pharmacists) in regards to medication management in PwD and the role of community pharmacists in supporting PwD to manage their medication (34). Framework analysis, which has been specifically designed for applied qualitative research that commences deductively from specified aims and objectives, was the selected method used to organise and make sense of the data (35,36). NVIVO software was used to manage the data.

TM and IM independently reviewed the transcripts and coded several interviews individually. Disagreements on the interpretation and analysis of the data were then discussed between TM and IM until consensus was achieved. A systematic cross-comparison analysis was undertaken by TM, and reviewed by IM to identify the similarities and differences between the different participants

and to develop a set of themes which represented the whole corpus of data. TM and IM then discussed and agreed the final structure of the matrix for the analysis.

3.3.1.1. Inclusion criteria

Informal carers were eligible if:

- They had provided or still provide some sort of assistance with medication management to a person who has been diagnosed with dementia and is living in the community;
- They do not receive any sort of payment for this role (excluding receipt of carers' allowance).

Health and social care professionals were eligible if:

- They had been in contact with or had been providing assistance to people with dementia

3.3.2. Interpretative phenomenological analysis

An ongoing Interpretative phenomenological analysis (IPA) of the experiences of eight informal carers living with someone with dementia (37) informed the results. Interviews with the informal carers meeting the inclusion criteria set for the IPA study were identified from the initial 11 interviews conducted with informal carers. IPA was the selected method of analysis in order to understand how informal carers make sense of their individuality and their lived experiences of dementia, medication management and relationships with healthcare professionals. IPA is a method commonly used that attempts to understand how participants make sense of their experiences in a critical and interpretative way (38). In addition, analysing the data by means of IPA allows the researcher to have a more active role in the whole process of data collection and analysis (39). In fact, IPA embraces the role of the researcher as being central and as having explicit effects on the whole project (40).

3.3.2.1. Inclusion criteria

Informal carers were eligible if:

- They were the main carer of someone with dementia and were living with this person
- They were not receiving any sort of payment for their caring role

4. Results

These results focus on the framework analysis; the ongoing IPA, which focusses on understanding how informal carers make sense of their role, has informed this analysis. Three main themes were identified. First, interviews with the informal carers and PwD described the key challenges experienced by PwD and their informal carers in relation to medication management. Second, informal carers, PwD and HSCP shared valuable perspectives about the process of medication management in PwD dwelling in the community and how it could be improved. Lastly, participants described how the role of community pharmacists could be developed to improve medication management.

4.1. Key challenges experienced by informal carers and PwD

The interviews with informal carers and PwD provided detailed information on the challenges that informal carers and PwD experience on a daily basis in the whole process of managing the medication. According to the analysis, challenges experienced by PwD and their informal carers are related to different areas and aspects of their lives and relationships i.e. challenges related to the caring role; challenges related to dementia itself; challenges related to healthcare professionals; challenges related to complexity of the medication management process.

4.1.1. Key challenge: The caring role

A number of carers interviewed reported that they had little problem in terms of the practicalities of managing the medication (*Informal carer – participant [pp] 1, Informal carer -pp2, Informal carer -pp3, Informal carer – pp4, Informal carer - pp6*). Although it is a complex process, by adopting a very organised routine, in some cases with the help of compliance aids, participants reported that the practical aspects of managing medication did not have any impact on their lives – “*No, not really [managing medication impacts my life] (...) I’ve got it all sussed out*” (*Informal carer – pp3*). Some participants explored this idea even more and stated that the act of taking care of someone’s medication “*becomes a way of life...Intrinsic part of you in the end (Informal carer - pp1)*”. However, there is still an emotional burden associated with taking care of someone with dementia and the health issues associated with it:

"[Regarding a strong deterioration of the person with dementia's mobility] So that's the important thing that I've got to deal with, I've got to attend to, I've got to see to and, you know, I'm frustrated about, I'm unhappy about, I'm concerned about" (Informal carer – pp14)

The emotional burden on the carer is exacerbated by the ineffectiveness of the medication for dementia. Seeing that all their effort to ensure the medication is taken at the right times and doses does not result in a health improvement often leads to frustration. This was clearly stated by one of the carers:

"I was frustrated with myself - why with the medicine and she was getting worse and worse. She was just crying in her bed herself." (Informal carer – pp25)

In spite of the emotional impact that being an informal carer brings, carers expressed an obligation to keep being responsible for managing the medication of the person they are looking after:

"Sometimes I feel fed up but what can I do? That is my duty." (Informal carer - pp27)

This emotional impact on the carer may be even more evident when they are forced to make decisions about administering medication. Without sufficient training, some informal carers found making decisions about the dose or time of medication extremely stressful:

"And now I discovered we've run out of brown [Warfarin] and they didn't bother to give us a prescription for it and it was the weekend, and I was going to go to the doctor but what I did was I've got a pill cutter. I cut the blue into two, I hope that's the correct dosage, I don't know." (Informal carer - pp14)

In fact, some informal carers questioned the appropriateness of the medication regime of the person they cared for and felt that sometimes, the medication that had been prescribed was excessive or even inadequate:

"[Doctor said] every three days, but I don't give it to her every three days because it's a morphine patch, it's for pain. She isn't saying that she's...any pain. Following the prescription she'd be taking 8 paracetamol a day which I think is far too much to be honest with you." (Informal carer - pp16).

Informal carers may have their own health problems and therefore have to manage the medication of two people; themselves and the person they care for. The majority of the participants agreed that having to manage both regimens can be difficult as there is *“A lot to think about.” (Informal carer - pp3)*. Interestingly, informal carers reported that they prioritised accurately administering the medication of the person they cared for:

“I forget my medicine but I never forget his medicine” (Informal Carer - pp 27)

4.1.2. Key challenge: The symptomatic effects of dementia

According to the informal carers, the characteristics of dementia - behaviours and cognitive problems – can increase the challenge associated with managing medication. If someone with dementia refused medication, informal carers found this a challenge; it also made it difficult to ensure the intake of all the prescribed medication:

“and then make sure he has to have his tablets, of course, two before he goes to bed. “Well, I’m not taking them.” “But you have to take them.” “I’m not going to take them.” And he’ll go upstairs without them, so then I either have [to] go back up with them or manage to get him back down to take them before he goes. Sometimes he does, sometimes he doesn’t. And then I think, “Oh, I can’t be bothered with this, do without your tablets.” (Informal carer - pp4)

The informal carers identified that adherence may be very difficult partly because the person with dementia may not understand the need or the importance of medication. This was corroborated by some PwD interviewed. One particular participant justified his lack of understanding about medication with the amount of medication that he needs to take:

“I wouldn’t know which ones to take, there’s too many of them.” (Person with dementia - pp1).

This quote illustrates that (due to cognitive impairment) PwD may be very dependent on the informal carers, particularly if the regimen is very complex.

4.1.3. Key challenge: The health and social care professionals

The data gathered reveals that the way HSCP work and their approach to dementia and PwD may

impact the informal carers' role. Although many informal carers described positive experiences with clinical staff, they mentioned that, in some cases, clinicians failed to adequately explain the disease:

"[Did not tell me what dementia was] No, not in the beginning, not to me, I have got the full record nearly 5 years, 6 years nobody mentioned that she is suffering from dementia (...) some people are facing silently (...) those who are not given the advice [about what is dementia]" (Informal carer - pp25)

Informal carers also mentioned doctors' lack of time when speaking about the challenges they face on a daily basis. In some cases, informal carers highlighted they had faced some difficulties in booking appointments to see a doctor to discuss medication problems. This lack of access to health professionals was seen as a barrier to effective medication management:

"This is what I feel I need to see Dr X, I really do. I feel that the tablets that she's on, they are not doing anything. I often wonder, sort of, to experiment and not give her any tablets at all for a week and see what the outcome would be. But then it might be dangerous. It could be you know, she could just fall off the planet. This is why I want to speak to him. But it's like trying to see the Pope!" (Informal carer - pp2)

Regardless of any flaws in the relationship and communication with the doctor, the majority of the informal carers stated they would always seek medical advice before they would stop giving any medication or making any significant change to the medication regime.

Some informal carers and PwD highlighted that they have experienced a lack of consensus amongst clinicians. This lack of consensus forces the informal carer to make a decision on which opinion to follow increasing the stress and difficulty associated with medication management. This problem was compounded by the complexity of care involving multiple prescribers:

"I think I would go back to the doctor before I stopped taking anything and I know they have different opinions (...) the specialist I saw this time is one of the team, the same team, but he said, "It's my opinion you should stay on those two tablets you've been taken off." He said, "I don't understand why you've been taken off those. In my opinion", this was his very words, "There'll be an M around a lot longer if you stay on those two tablets. You see, even in the same team, you've got some people

who believe this is right and some people believe this is right and either of them could be right.”
(Informal carer - pp1)

4.1.4. Key challenge: The complexity of the medication management process

Informal carers appear to find the management of complex regimens when a number of tablets are taken at different times of the day particularly challenging:

“So all these [health issues] require medication...It's keeping them separate that is the real problem.”
(Informal carer - pp14)

From the informal carers' accounts, it can be understood that medication management is more than just administering the right tablets at the right times; they also need to control the stock/supply of tablets and make sure that they do not run out of medication. As one participant said, it is important to *“make sure that you have got enough tablets to last you that time”* (Informal carer - pp3).

“I think the main problem with the medication was having to go and get it and remembering, “Oh, there's only that many left of that particular one, I'd better order some more.” And I seemed to be up and down there twice a week.” (Informal carer - pp4)

To conclude, informal carers experience several challenges when it comes to managing the medication of someone with dementia. These challenges are not only related to the complexity of the medication and the disease, but also due to lack of adequate support from clinicians. These aspects need to be addressed in order to improve their medication management skills and reduce the potential for medication errors.

4.2. Improving medication management in PwD

Another objective of this research was to understand and explore how medication management in PwD can be improved. Participants shared some suggestions that could be implemented in order to improve the life of PwD and their informal carers by decreasing the medication management burden. According to the data, the medication management process in PwD can be improved by targeting several areas such as the HSCP, medication reviews, the informal carer and the practicalities of medication management.

4.2.1. Focusing on HSCP to improve medication management in PwD

Many HSCP (including pharmacists and GPs) and informal carers interviewed identified that the support given by HSCP to PwD could be improved. Initially, early intervention and continued provision of support by HSCP is seen as positively related to the patient's ability to manage his or her medication:

*"It's, like, identifying these people so you can get the services in before there's like a crisis, really."
(District nurse -pp13)*

Informal carers, and most of the HSCP, highlighted the importance of communication. One informal carer highlighted the importance of having a clinician able to *"answer all my questions"* (Informal carer – pp2) so he could feel supported.

Providing explanations about the medication and treatments to PwD and their informal carers is a key aspect to improve their understanding of the situation and consequently decrease the risk of medication errors:

"So that would be helpful, if it was just what they're prescribing for you, was just a little bit more...explanation to it yes... And then it's easier to take that in, isn't it?" (Informal carer – pp1)

HSCP agreed that lack of communication increases the risk of medication errors:

"And if they've sat there in a consultation and me or anyone else who's seen them has thought "Oh, they've completely got that" and then a few months later someone else sees them and then... although the drug is no longer on their computer screen and in their medical records, at home they've still got boxes of tablets and they're still taking them and they shouldn't be" (GP - pp15)

According to some HSCP, strategies such as writing down information about the medication and instructions about how and when medication needs to be taken could be used as a way to help ensure the carer and the person with dementia understands all the information about the medication:

“getting written instructions, pictures and making sure that their, you know, spouse or their family understand what to do.” (Nurse prescriber and Practice nurse - pp9)

HSCP identified that a co-ordinated response involving several HSCP, was needed to support medication management:

“Well, if they’re having problems taking it at the right time then I would say social services because they’d need prompting to take it. If it was because they couldn’t open bottles or they were getting pills mixed up, because you, like, you might get several tablets that look the same. You know, so that would be the pharmacist because you need identification. If it was because, like with PRN medication, you would maybe need a nurse to help them identify when they needed certain drugs.” (District nurse - pp12)

According to one informal carer, the support provided by clinicians to PwD and their carers needs to take into consideration the different cultural traditions and religions that these patients may have. According to this participant, a doctor-patient relationship should be based on understanding the patients’ background:

“whoever is looking after [PwD] if they [clinicians] are not aware of these issues, cultural issues, religious issues and traditions (...) then it's a big problem (...) you have to build the confidence according to their traditions or religion so it plays a major part in that situation if you're not aware [of cultural and religious aspects].” (Informal carer from the BME community – pp25)

Even more, this participant highlighted that it is important to take into consideration that some people from South Asian backgrounds may not have a perfect understanding of the language and may find it difficult to understand the condition, the medication needed and the support available:

“[about the fact that some people have never heard of dementia and the treatments available] specially the South Asian people have little knowledge about English.” (Informal carer – pp 25)

4.2.2. Focusing on Medication Reviews to improve medication management in PwD

Medication reviews that include explaining the details of the medication were viewed as having potentially a positive impact on the patient’s medication management process. One carer

mentioned she would like to have *“a little bit more...explanation”* (Informal carer – pp1) about medication and how it should be taken. However, HSCP (especially nurses and GPs) mentioned that they do not have enough time to spend with the patients to review their medication adequately:

“[providing a detailed review of medication] But that's difficult in itself because you've got them in for a snapshot of time. So that, in a 20 minute appointment and looking at their medication is just one part of that. And actually, just saying to somebody, you know, how are you managing with your tablets, any problems? Probably, in that instant, most people are just going to say, unless they know there is a problem, most people will probably say, "No, no, it's fine, I'm taking them". But actually, you know, I don't know how in depth we go, really, as to whether, "Are you taking them correctly"? "Are you taking them at the right times of day", that type of thing.”(Practice nurse and ex district nurse - pp7).

Not doing an adequate review of the medication management process has a negative impact on the informal carer and on the person with dementia. Additionally, HSCP need to co-ordinate any review and share relevant information:

Although the information does come back to us through the GPs, it may not always be the type of information that we always want. Like, there may be changes to the medication needs, apart from what the doctor's view. But that patient may not be as well adherent but they may be hoarding medication and not presenting it to the doctor.” (Pharmacist - pp23)

According to most of the HSCP interviewed, medication reviews should be conducted in the patient's home. Going to the patients' environment and seeing the strategies they use to manage their medication gives HSCP a more complete picture of the whole process:

“that's easier isn't it when you are out there seeing them in their home. It's very difficult when people come in because you have no idea really...like I say, things can sound very chaotic but actually when you are in there, you think, "Oh, no, it's OK, it's working". It's very difficult when you are not actually seeing it for yourself.” (Practice nurse and ex district nurse - pp7)

Many HSCP (nurses, GPs and pharmacists) argued in favour of focusing the medication review on the patients' situation and decreasing the complexity of the regimen:

"If you've got a choice of inhaler but have these twice a day...or there's one that's once a day you'd, hopefully, go for the one that's once a day if it carries the appropriate medication. So, it's just simplifying everything (...) Get them the best medication possible, make it simple and then they are going to use it." (Nurse prescriber and practice nurse - pp9)

On a similar note, based on the testimonies of some HSCP, the formulation of medicine is also an important consideration. For instance, the size and taste of the tablets can be a barrier to adherence as some PwD *"get wise to it and don't like the taste."* (Mental health nurse - pp18)

"Clarithromycin antibiotic is fairly large, 500mg. So they attempted to take it and, after a day of attempting to take it, the patient was getting very frustrated because they had difficulty swallowing it and it was coming back up." (Pharmacist - pp23)

4.2.3. Focusing on the informal carer to improve medication management in PwD

The majority of the HSCP interviewed emphasised that targeting the informal carer is the best way to improve the medication management process in PwD dwelling in the community. According to many HSCP, it is important to involve the carers because most of the times the medication management process is solely dependent on them, *"it's mainly relying on the carers."* (GP – pp5)

"it usually comes down to their carers. I mean, in my experience, it's always, you know, perhaps the wife or the husband who are very elderly and quite frail but cope fantastically, from week to week." (Nurse prescriber and practice nurse - pp9)

Furthermore, empowering and supporting informal carers was viewed as being a direct way to improve the medication management process:

"If they have difficulty, then they should have a contact number and immediately have any help. Because they do get frustrated. "Doctor, you've given me this but I can't make her take it". So that's where the help needs to be improved, empowering carers. (...) You can't empower the patients because they're already losing them. Yes. Empowering the carers is the one thing that we could do." (GP – pp5)

From the informal carer's perspective, the informal carer is also an active part of the whole process of dementia care, and when supporting someone with impaired cognition and it is vital that clinical staff *"listen to the concerns of the relatives."* (Informal carer – pp14)

4.3. The role of the pharmacists

4.3.1. Barriers to community pharmacy

HSCP identified the role of pharmacists in giving advice on medication. However, informal carers and PwD tended to focus on practical aspects of the role, such as home delivery of medication and simply viewed the role of the community pharmacist in terms of the supply of medication:

"[community pharmacists and medication] they just provide it, don't they...(Informal carer – pp1)

HSCP (including nurses, general practitioners and paid carers) also identified that people may not be aware of the benefits of going to the pharmacist to seek help and advice on medication:

"So I think people probably aren't aware of community pharmacists. I think probably a lot of people just see them [as people] who dish the tablets out, not [someone they go to] for advice or whatever." (Practice nurse and ex district nurse - pp7)

As a suggestion to overcome this issue, some informal carers and pharmacists mentioned that it comes down to the pharmacist to be more proactive and promote their services more and *"bring themselves a bit forth"* (Informal carer – pp1) and not being someone who is just *"behind the counter where [people] don't see them "* (Informal carer – pp1).

All four community pharmacists identified the need to have access to the patient's medical records in order to have more information about the patient and consequently improve the support they provide to PwD and their informal carers:

"Well, I think if we had access to medical records we would know more about the patient's journey of where they've been, who they've seen. And we'd be better able to support them." (Pharmacist - pp21)

Pharmacists need to play a more active role in the multi-disciplinary team that supports PwD living in the community. Non-pharmacist HSCP believe that pharmacists are under-utilised. In fact, several non-pharmacists HSCP interviewed claimed that *“we could use the pharmacist more”* (GP - pp19)

“The main thing is if the pharmacist is attached to the practice and to the patient that would be great. (...) I mean, why haven’t they [doctors] got such good relationships with pharmacists... here’s the store of knowledge (...) Well, I think we’re very lucky in this country in that we do have a community network of expert pharmacists who are under-utilised, whose expertise is under-utilised...So, the improvement will come when it’s made very clear that practitioners are expected to have this level of dialogue.” (GP – pp8)

Including community pharmacists in this clinical loop of support could help pharmacists develop a clinical role and enable them to give further support to PwD and their informal carers:

“Well, I think the community pharmacists are left out of the clinical loop, the loop of communication between GPs, specialist nurses and the hospital...they don’t realise the potential for the community pharmacist to be a referral, you know, to co-ordinate.” (Pharmacist – pp 21)

4.3.2. Optimising and improving the role of community pharmacists: a potential new role

Some suggestions that can be explored as an eventual new role for community pharmacists were gathered. One practice nurse highlighted the idea of a *“named pharmacist”* designated to each person within the community, who would be specifically trained in dementia with the knowledge to educate and provide practical support to people with dementia and their informal carers:

“somebody in pharmacies that oversees all dementia patients so that every patient who is diagnosed with dementia, their prescriptions go to that particular pharmacy and a particular pharmacist within that pharmacy is responsible for that. Are they a named contact for families that if they are concerned they can contact that particular pharmacist? So that, as well as having a named nurse and a named GP, do they have a named pharmacist (...) if you had a pharmacist who was responsible for that patient's medication, then at least you would have a contact. (...) Then it can be a bit like, “Well hang on a minute, who...is actually making sure that this patient is taking their medication”? And maybe at that point, that's where a community pharmacist could take on a role of monitoring medication. I don't know.” (Practice nurse and ex district nurse - pp7)

Training pharmacists towards specialisation in dementia was viewed as important:

“And I think there could be a role for specialist pharmacists for dementia. Which would mean that the pharmacist and the staff in the pharmacy have a little bit extra training.” (Pharmacist - pp21)

Pharmacists often have close relationships with people within the community which is clearly an advantage. An informal carer suggested that community pharmacists could act as a gatekeeper *“to get in touch with the doctor and try and get more appointments” (Informal carer – pp2)* as sometimes (as seen above) some people may have difficulties in getting in touch with their doctors.

Several HSCP (mainly community pharmacists and GPs) suggested the idea of having community pharmacists visiting people’s houses to understand how they are coping with the medication in their own home:

“so offsite provision of pharmaceutical services and also we will be able to find out from, for example, going to the patient's home, how their environment is, how their Health Care and Social Care might be coming together to ensure that the patient is taken care of holistically as opposed to just making management specifically.” (Pharmacist - pp23)

Informal carers supported this potential role, highlighting that this would be *“great help if a person was living on their own with dementia” (Informal carer – pp1)*. Similarly, another informal carer mentioned that *“if people are alone, or, like, the carer isn’t up to doing it, or feeling it’s too much” (Informal carer – pp4)* then having a pharmacist to help would be an advantage.

This idea of the *“pharmacist out of the pharmacy”* would also mean engaging with the dementia population more generally through groups and events. Having the presence of trained community pharmacists at charitable events or in voluntary groups would, according to some participants, be a great advantage and a way to improve medication management in PwD:

“So is more of a holistic check and engaging with the local population through events, through charitable events but also keeping closer ties, closer voluntary people groups, charitable events,

Council. So the scope is endless but it takes a pharmacist, for example, out of the four walls of the pharmacy into the community where they belong.” (Pharmacist - pp23)

Community pharmacists were clear when stating the benefits that this could have. Seeing and engaging with a person with dementia in his or her own environment and keeping closer ties may enable professionals to have a better understanding of their situation and struggles. This would enable health professionals to put strategies into place to tackle those issues:

“occasionally, sometimes you might just need to see the person, or, sometimes if you do meet the person, then things get said that might not just be said by the carer.” (Pharmacist - pp22)

However, PwD are more likely to be house-bound and consequently may have more difficulty in accessing a community pharmacist, and generally the current funding model doesn't support this type of service:

“Yes, so again, if we were able to go into a patient's home easily and that was funded as a service, that would mean that the patient would be more relaxed and would be able to take me to where they store their medication, show me how much stocks of medication they've got and they would just be a little bit more relaxed than coming into a consultation in a pharmacy.” (Pharmacist - pp24)

In some areas the service is already running and reportedly showing positive results:

“Yes. I mean, currently in my part of London, we do not have a commissioned service where we can do medicines use reviews at the patient's home. However, my colleagues in the neighbouring (area) of X, next to mine do have it. (...) And it's shown to be a valuable service whereby a healthcare professional, a pharmacist, specifically, would be able to go to a patient's home and do a review at the patient's side, and also, how they are getting on with their medication, in case they are housebound or having difficulty.” (Pharmacist - pp23)

Developing the role of support staff, better use of technology and the current initiative to have pharmacists working in GPs surgeries were also suggested as approaches:

“However, things that are changing, they are using the staff members of the pharmacy teams more so, enabling the pharmacist to not be in a pharmacy. That could be extended with supervised, sort of, supervision through electrical means, TV monitors and what not, and currently, it is happening and there is recently funding available from NHS England to allow pharmacists to start working in GP's surgeries and NHS England are going to be partly funding that, (...) to ensure that patients are getting the best out of their medication, taking the right medication too, ensuring that the best medicine management is possible for that particular group.” (Pharmacist - pp23)

5. Discussion

The whole process of managing the medication in a person with dementia is complex and at times extremely complex. In spite of the literature available exploring the topic of medication management in older adults (15,17,41) few studies have focused on informal caregivers and PwD (23,32,42). This research found that medication management in dementia appears to be an area with potential for improvement and there is a clear need for further exploratory research.

We found, like other studies, that with increasing cognitive impairment medication management in PwD becomes the responsibility of informal (family) carers, who frequently have little or no knowledge of medication (15,17,43,44). In these cases, having to manage the medication brings several day to day challenges, and the greater the complexity of the regimen, the greater the challenge for informal carers (43). The challenge was compounded, because most of the time informal carers also have their own medication regime to manage. Caring for someone with dementia who lacks understanding of the need for medication and refuses to take it was one of the most common challenges highlighted by the carers. Similar conclusions were found in other studies (15,17,43). Having to control the stock and supply of medication and making sure they have enough medication is also a constant concern.

Informal carers and PwD mentioned having poor knowledge about medication and highlighted a lack of appropriate support from HSCP. As found in the past (15,43), sometimes HSCP do not spend enough time with informal carers and PwD explaining the details and importance of the medication. One issue highlighted that was also found elsewhere (43) was that sometimes different clinicians have may different opinions regarding the medication regime. This is particularly problematic because patients may not always see the same HSCP (44).

Although only 3 people from ethnic minorities were interviewed, they spoke about particular aspects that are not often explored and need consideration. This included the importance of taking into consideration the different cultural traditions and religions of the patients as they play a very important role in the doctor-patient relationship. The informal carers and PwD's decision whether to follow doctors recommendations may depend on whether they feel clinicians understand and respect their background. Moreover, informal carers from the BME community may not have a clear understanding of the English language and consequently may not be able to understand the instructions given by clinicians on medication and treatment. This confirms the finding in a study involving European ethnic minority informal carers that found that language barriers could increase medication management difficulties (43).

Although there are studies exploring the role of the community pharmacist in medication management (25,45-52), there is a lack of studies specifically focusing on how that service can be expanded and improved when it comes to PwD supported by informal carers (23,43). Although other studies have also identified the under-use and an under-exploitation of the knowledge of community pharmacists and the potential to develop their role (6,25,52-54), this study may be the first to explicitly focus on exploring ways to improve and expand the role of community pharmacists in medication management for PwD.

This exploratory research found potential to expand the positive impact that community pharmacists are having in the community. There was a general agreement that PwD living in the community would benefit from more active support from community pharmacists. Not only educative support within the pharmacy, but more practical support such as going into people's houses to help them organise the medication and set strategies to avoid medication mistakes, as previous work with older people with mental health problems identified (55). According to clinicians interviewed, this would allow the healthcare system to identify people in need of special assistance.

According to the data gathered in this study, there are several barriers to such a role for community pharmacy. PwD may have difficulties accessing appropriate pharmacy services, because generally the current funding model only allows MURs (medication use reviews) to be conducted in the pharmacy (56). Furthermore, current funding only supports MURs, which are not full clinical reviews and focus on adherence to medication (57). Access was identified as a barrier in another study which

investigated the medication management concerns of ethnic minority informal carers of PwD (43). This study found that even if the person can access the pharmacy, the physical layout of the store may inhibit interaction (43). Nevertheless, our findings show that if access to community pharmacists could be improved this could potentially show positive results.

PwD and their informal carers need to have more information to understand that community pharmacists can provide medication advice and help with medication management strategies including the emergency supply of medication. Similarly, other studies have also shown that the general public is frequently unaware of the potential role of community pharmacists in medication management including the availability of MURs (44,58,59). This again re-enforces the need for community pharmacists to adopt a pro-active approach. Crucially, as seen in other research, lack of access to patient records is also a barrier to community pharmacists supporting PwD and their informal carers (25,50,60). Currently, community pharmacists do not have access to full records; access via an Electronic Health Record is planned (Summary Care Record [SCR] in England, the Emergency Care Summary [ECS] in Scotland and the Individual Health Record [IHR] in Wales). Access to the SCR is currently being rolled out; in December 2016, over 50% of pharmacies had access (61). The SCR is a “read only” record i.e. currently pharmacists can't record their actions or interventions; it contains key clinical information such as medicines, allergies and adverse reactions, and may include diagnoses and test results (62).

Using community pharmacists to educate and assist the population could be an important step to reduce adverse events associated with the inappropriate use of medication (63). It was highlighted by several HSCP that training pharmacists in dementia care would produce positive outcomes not only to PwD and their carers but also to other HSCP. Involving pharmacists in the clinical loop of treatment, and allowing them to have a more collaborative approach to dementia care is essential, as other studies have identified (55). However, as previous research identified there are insufficient community pharmacists trained and experienced in dementia to provide the required support to PwD and their informal carers, and other HSCP (6,25,50).

Pharmacists other than community pharmacists including pharmacists employed by the local Clinical Commissioning Group, Mental Health Trust, a GP practice or specifically employed to support a number of community pharmacies could provide the required support. However, the

community pharmacy that supplies the medication would still need to be a key element of any model.

This study supports the recent move from NHS England to have pharmacists based within GP surgeries to support the management of people with long term conditions (64,65). Generally, PwD and their informal carers agreed that having extra help to manage this long term-condition and having access to tailored and specific advice in relation to medication and treatments would be beneficial. HSCP interviewed also agreed that PwD and informal carers would benefit from having more information about medication and more frequent advice on treatment (66). Having pharmacists and GPs co-located on the same site could improve the joint working relationship and consequentially the whole process of medication management in PwD (50,51,67) – similar conclusions were drawn from another study in people with hypertension (68). Pharmacists working in GP surgeries will naturally have access to the full medical record if they are working as part of the general practice team involved in day- to-day medicine issues.

Department of Health policy aims to develop the role of community pharmacy in medication management (29). Data from this study increases the understanding of the potential role of community pharmacy in dementia care and barriers to such a role, and shows that patients could benefit from additional high-quality services. Therefore, this research can inform future debate and research regarding the potential role of community pharmacists in this area, and influence policy development in healthcare.

5.1. Implications for practice and policy

This research enables HSCP from different areas to have a practical understanding of the challenges that PwD and their informal carers face every day. Moreover, it can be a starting point for the development of interventions focusing on empowering the capacity of informal carers to manage medication effectively thus reducing their emotional burden. Our research indicates that community pharmacists must work outside the “four walls” of the pharmacy to support PwD and their informal carers manage their medication. This “work without boundaries” should include medication reviews in the patient’s home and needs full access to clinical records. Pharmacy must raise its profile and promote its potential role more effectively to the general public.

This research has a number of implications for policy. Policy should focus on supporting informal carers of PwD with medication management. Community pharmacists will be a key part of any

support mechanism. Therefore, policy and the funding associated with policy should enable community pharmacists to support PwD and their informal carers living in the community with medication management. Research policy should reflect the need for further research in this area.

5.2 Further Research

We found limited research in this field. Future research needs to build a robust base of evidence on community pharmacy, and how quality and a patient-centered approach can be built into services. This research should be set around the MRC framework for developing a complex intervention (69). The literature including the grey literature and further interviews should refine an intervention based on collaborative care involving suitably trained accessible community pharmacists. The feasibility of trialling the intervention should be tested, and if feasible a full clinical trial of the intervention should be conducted. Similarly to other studies in the field (43,70), this study also identifies the need for further research and recognition regarding the challenges faced by people from BME communities.

Access to patient records is needed for community pharmacists to start to develop their role (25,50,60). Thus, the impact of the SCR needs evaluation including how access to SCR affects the professional services provided by community pharmacy for PwD.

5.3. Strengths and Limitations

As far as we are aware this study may be the first UK study in the field using a triangulation of perspectives from different HSCP, informal carers and PwD to explore medication management in PwD. Participants were recruited from several geographical locations in England and data saturation was achieved.

It is important to highlight that this is qualitative study, so that, the findings are context-bound to the informal carers and HSCP interviewed and the setting in which the study was undertaken (66). Secondly, this study was limited in that its sample of participants was not particularly rich in terms of ethnic diversity. Efforts were made to reach more people from different ethnic backgrounds, such as people from the BME community. However, only three people from these groups agreed to participate in this study. We believe that further research would benefit from exploring the perspectives of a more diverse sample.

This study also only considered the potential role of community pharmacists; however community pharmacists may not be the best placed healthcare professional to provide this type of service. Future research should explore the barriers and facilitators to different categories of pharmacists and other clinicians supporting PwD and their informal carers with medication management. However, this research clearly demonstrated the need for a collaborative approach and the community pharmacist is well placed to be a key element of this approach.

6. Dissemination and Communication Plans

6.1 Delivered Conference presentations

September 2015 - Hull Local Practice Forum. Presentation on the potential role of community pharmacists in supporting people with dementia living in the community with medication management. Highlighted some preliminary findings from the PRUK grant.

September 2015 – invited talk to Bradford University, Dementia Research Group. Presentation on key research priorities in dementia care. Included the key areas for further research identified in the PRUK grant.

6.2 Planned Conference presentations

European Society of Clinical Pharmacy/College of Mental Health Pharmacy.

6.3 Academic Publications Planned

Aston L, Hilton A, Moutela T, Maidment ID. Exploring the evidence base for how people with dementia manage their medication in the community: a mixed studies meta-synthesis. *Target journal BMC Geriatrics*.

Maidment ID, Aston L, Moutela T, Fox C, Hilton A. The Role of Community Pharmacists in supporting people with dementia manage their medication: a qualitative study. *Health Expectations (in press)*.

Moutela T, Maidment ID. An Interpretative phenomenological analysis (IPA) of the medication management experiences of informal carers living with someone with dementia. *Article in draft – target journal tbc.*

6.4 Associated Public Engagement Activities

September 2014 – British Festival of Science, Birmingham. Presentation on the challenges in relation to medication management and the potential role of community pharmacists.

140 word tweets of key findings and targeted mail outs to stakeholders and any associated literature.

We plan to send a copy of the report to the Alzheimer’s Society and promote via the local branch networks of the AS and Age UK. Currently we are planning presentations at Alzheimer's Society Memory Cafes and memory clinics. We also plan to work with the ARCHA (Aston Research Centre for Healthy Ageing) Research Participation which contains approximately 170 members of the public to disseminate the work to a lay audience. This will include producing user-friendly methods of dissemination.

7. Additional Resources

<http://dementiameds.com/> - website designed for informal carers of people with dementia to help them support medication management. Versions in English, Italian and Macedonian.

www.aston.ac.uk/medrev - website with details of a collaborative pharmacy-health psychology study with the overall aim of improving the use of psychotropics in people with dementia.

Polypharmacy and Deprescribing Webkit on [https://www.prescqipp.info/polypharmacy-deprescribing-webkit?utm_source=PrescQIPP%20Bulletin%20List&utm_campaign=0103f93aae-April newsletter subscribers 2016&utm_medium=email&utm_term=0_009717c01d-0103f93aae-357421297](https://www.prescqipp.info/polypharmacy-deprescribing-webkit?utm_source=PrescQIPP%20Bulletin%20List&utm_campaign=0103f93aae-April%20newsletter%20subscribers%202016&utm_medium=email&utm_term=0_009717c01d-0103f93aae-357421297)

This web-site (PrescQIPP) contains guidance on effective medication review, prioritising patients, suggestions for who can conduct a medication review, how to engage patients including how long the consultation should last.

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Appendices

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Appendix B – Further Demographic Details of participants

| Participant ID | Participant number | Interviewee | Gender | Location | Ethnicity |
|----------------|--------------------|--|-------------------------|---------------|--------------|
| 711-0011 | 001 | Person with dementia & Informal carer | Male (M) and Female (F) | West Midlands | White (both) |
| 711-0012 | 002 | Informal Carer | M | South West | White |
| 711-0014 | 003 | Person with dementia & Informal carer | M & F | West Midlands | White (both) |
| 711-0015 | 004 | Informal carer | F | North East | White |
| 711-0016 | 005 | General Practitioner (GP) | F | North East | White |
| 711-0017 | 006 | Informal carer | F | North East | White |
| 711-0018 | 006 | Practice Nurse | F | North East | White |
| 711-0019 | 008 | GP | M | London | White |
| 711-0020 | 009 | Practice Nurse | F | West Midlands | White |
| 711-0021 | 010 | Paid Carer | F | West Midlands | White |
| 711-0022 | 011 | Person with dementia | M | West Midlands | White |
| 711-0024 | 012 | District Nurse | F | West Midlands | White |
| 711-0023 | 013 | District Nurse | F | West Midlands | White |
| 711-0026 | 014 | PwD & Informal carer | M & F | West Midlands | White (both) |
| 711-0028 | 015 | GP | F | North West | White |
| 711-0031 | 016 | 2 Informal carers (caring for the same person) | M & F | West Midlands | White (both) |
| 711-0035 | 017 | Paid carer | F | South East | White |
| 711-0027 | 018 | District/Mental Health Nurse | F | West Midlands | White |
| 711-0030 | 019 | GP | F | West Midlands | White |
| 711-0036 | 020 | Paid carer | F | South East | White |
| 811-0088 | 021 | Community pharmacist | F | Yorkshire | White |
| 811-0089 | 022 | Community pharmacist | M | Yorkshire | White |
| 811-0084 | 023 | Community pharmacist | M | London | South Asian |
| 811-0090 | 024 | Community pharmacist | F | South West | Not known |
| 711-0037 | 025 | Informal carer | M | Yorkshire | South Asian |
| 711-0038 | 026 | Informal carer | F | Yorkshire | South Asian |
| 711-0039 | 027 | Informal carer | F | Yorkshire | South Asian |

Appendix C – Semi-structured Interview Schedule

1. Interview schedule for informal carers/PwD: A qualitative scoping study exploring the role of the community pharmacist in medication management in people with dementia dwelling in the community.

This semi-structured interview will consist of open-ended questions, which are split into four sections. However, these questions will depend upon how much detail the participant wants to give. Due to the sensitive nature of this topic, participants will take some direction over this interview and some questions may be missed out or expanded upon. Minor amendments may be made as the interview progresses as issues may arise that the researcher had not considered.

Introduction

Before we begin this interview, could you confirm whether you are caring for someone with dementia?

Thank you for taking part in this interview, I really do appreciate the time you have given. Before we begin, I want to make it clear that if you wish to skip any question(s) during the interview; or if you want to stop the interview, all you have to do is say; you don't need to give any explanation for doing so.

Are you happy for me to begin?

Can you tell me a bit about yourself? For example, do you have family or do you work?

Can you describe what a typical day involves for you?

The next few questions are going to be in regards to medication.

(If PwD) Can you describe to me any practical issues/concerns (if any) you find with taking medication?

(If carer) Can you describe to me any practical issues/concerns (if any) you find with assisting somebody with their medication?

Can you describe to me any strategies you use to organise medication?

Prompt: From sorting your medication to taking it or assisting someone to take it; are there any particular methods / procedures you use to do this?

In this next section, I'm going to ask a few questions with regards to taking (if interviewing the PwD) or assisting somebody (if the carer) in taking medication. I want to remind you that these questions are to help us better our understanding of how people feel about medication. Your replies will be treated so that no one will be able to identify that these are your answers.

(If PwD) Can you tell me about a time, if any, you've decided not to take your prescribed medication?

(If Carer) Can you tell me about a time, if any, you've chosen to not give prescribed medication to your (whatever the relationship)?

Prompt: Do you think that people should always take their prescribed medication?

What would you describe as the benefits of taking medication?

Prompt: In your opinion, are there any benefits to not taking medication?

Can you think of any reasons why people would not take their prescribed medication?

The next section of questions will be about your experiences with medication:

In your opinion, does managing your medication affect your daily life?

Have you had any changes to medication over time?

If yes: can you tell me a bit about that and how it made you feel?

If no: Do you think change in medication over time would have an effect on someone in your situation? If yes, in what way?

(If carer) Have you become more involved in assisting in the organisation of medication?

If yes: how did that make you feel?

We are moving onto the last section of the interview now; this section is to do with your opinions and experiences with Healthcare Professionals:

Can you tell me about the experiences you've had with Healthcare Professionals (i.e. GPs, pharmacists, social care workers) over the past couple of years?

Prompt: Have you had any notable experiences with Healthcare Professionals?

Can you describe to me your feelings about the level of support you have in regards to Healthcare Professionals helping you with medication?

How do you think Healthcare Professionals could improve support to people with dementia and their carers when it comes to helping with medication management?

Prompt: Do you need support from Healthcare Professionals in regards to medication management? If yes, what kind of support would be helpful?

How do you feel about the future in terms of support from Healthcare Professionals in helping with medication?

Prompt: Do you think Healthcare Professionals need to be more involved in supporting people with dementia and their carers, manage their medication?

Prompt: What Healthcare Professional do you think would be most helpful in offering this support?

Thank you

Is there anything that you would like to add or any questions you would like to go back to?

END OF INTERVIEW

2. Interview schedule for Health and Social Care Professionals: A qualitative scoping study exploring the role of the community pharmacist in medication management in people with dementia dwelling in the community.

This semi-structured interview will consist of open-ended questions, which are split into three sections. However, these questions will depend upon how much detail the participant wants to give. Participants will take some direction over this interview and some questions may be missed out or expanded upon. Minor amendments may be made as the interview progresses as issues may arise that the researcher had not considered.

Introduction

Before we begin this interview, could you please confirm what your job title is?

Thank you for taking part in this interview, I really do appreciate the time you have given. Before we begin, I'd like to make it clear that if you wish to skip any question(s) during the interview; or if you want to stop the interview, all you have to do is say; you don't need to give any explanation for doing so.

Are you happy for me to begin?

Can you tell me what your current role is in regards to caring for people with dementia?

The next few questions are going to be about your experience of reviewing and assisting medication management for dementia patients and their carers that live at home (are not in residential care).

Can you tell me a bit about your experience of reviewing or helping people with dementia or their carers manage their medication?

From your experience and your own opinion, what would you say (if any) are the challenges in medication management for dementia patients and their carers?

Prompt: Practical challenges? How might it affect their lifestyle?

Do you feel that assisting/reviewing medication for people with dementia and their carers is a part of your role?

Prompt: Can you describe any facilitators or barriers that help or hinder you from assisting/reviewing medication?

The next couple questions are going to be about compliance/adherence to medication.

Can you tell me whether you've ever experienced patients who have dementia not adhere to prescribed medication?

Prompt: If yes, can you tell me a bit about this and how did you manage this?

What do you believe could be the potential reasons for non-adherence/non-compliance in people with dementia/ their carers?

The last section of the interview focuses on your opinions about current practice.

Can you tell me about your beliefs on the level of support available for people with dementia and their carers in regards to medication management?

How, in your opinion, do you think the service could improve?

Prompts: In order to make any improvements, what should take place?

In your opinion, can you describe to me the role that community pharmacy plays in medication management in people with dementia?

What do you think healthcare professionals' role is with supporting care for medication management in people with dementia and their carers who dwell in the community?

What are your expectations of healthcare professionals' future role in supporting people who have dementia and their carers with regards to medication management?

Do you anticipate much change happening in practice regarding this?

Thank you.

Is there anything that you would like to add or any questions you would like to go back to?

END OF INTERVIEW