

A qualitative scoping study exploring the role of the community pharmacist in medication management in people with dementia dwelling in the community

Final Report – July 2016

Authors

- **Dr Ian Maidment, Senior Lecturer in Clinical Pharmacy, Aston University**
- **Lydia Aston, Research Associate, Aston University**
- **Tiago Moutela, Research Associate, Aston University**
- **Dr Andrea Hilton, Senior Lecturer, Non-Medical Prescribing Programme Lead, University Teaching Fellow, Hull University**

Corresponding author: Ian Maidment, Pharmacy School of Life and Health Sciences, Aston University, Aston Triangle, Birmingham, B4 7ET, i.maidment@aston.ac.uk

This research was supported by a research grant from Pharmacy Research UK

Index

	<u>Page</u>
<u>Main Messages</u>	3
<u>Executive Summary</u>	4
<u>Main Report</u>	7
1. Context	7
2. Aims and objectives	8
2.1 - Aims	8
2.2 - Objectives	8
3. Approach and Methods	8
3.1 - Study design	8
3.2 - Meta-synthesis	9
3.3 - Exploratory research, sampling and recruitment	9
3.3.1 - Qualitative framework analysis	10
3.3.2 - Interpretative phenomenological analysis	11
4. Results	11
4.1 - Key challenges experienced by informal carers and PwD	12
4.2 - Improving medication management in PwD	16
4.3 - The role of the pharmacists	21
5. Implications /Discussion	25
5.1 - Implications for practice	28
5.2 - Further Research	28
5.3 - Strengths and Limitations	29
6. Dissemination and Communication Plans	29
6.1 - Delivered Conference presentations	29
6.2 - Planned Conference presentations	30
6.3 - Academic Publications Planned	30
6.4 - Associated Public Engagement Activities	30
7. Additional Resources	30
Appendices	32
Appendix A – References/ Bibliography	32
Appendix B – Demographic Details of Participants	37
Appendix C – Semi-structured Interview Schedule	38
Appendix D – Meta-synthesis paper	42

Main Messages

- With increasing cognitive impairment, medication management in PwD becomes the responsibility of informal carers.
- The whole process of managing the medication of someone with dementia was generally complex and challenging, which created both practical problems and an emotional burden for the informal carer.
- Informal carers need appropriate support from Health and Social care Professionals (HSCPs).
- Community pharmacists could provide further support to the informal carers of PwD with medication management.
- Community pharmacists need to work outside the physical environment of their community pharmacy to deliver such support.
- There is a clear need for further research to develop the mechanisms by which community pharmacists could provide such support, and then test the effectiveness of the mechanisms.

Executive Summary

Background

The number of people living with dementia is increasing rapidly. Dementia increases the likelihood of risk factors, such as comorbidity and polypharmacy, for adverse drug reactions; the presence of cognitive impairment also increases the risk of medication errors. With increasing cognitive impairment, medication management shifts from the responsibility of the person with dementia to formal (paid) or informal (family) carers. Informal carers may not feel equipped for such a role which they can find burdensome and stressful, worsening the quality of life of the carer and person with dementia. Community pharmacists may be able to support informal carers with medication management and the need for further research exploring this potential role has been identified. This project aimed to explore the perspectives of the key stakeholders to understand how community pharmacists can support PwD living in the community with medication management.

Method

This report used a qualitative approach with data triangulation from three studies (a meta-synthesis, qualitative framework analysis and an Interpretative Phenomenological Analysis) to provide a valid and reliable understanding of the objective of this report from different perspectives. 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.

Participants for the qualitative research were recruited from the Alzheimer's society, Dementia UK, local GP surgeries and local dementia support groups (including a support group for people with dementia in the black and minority ethnic [BME] community in Yorkshire). Snowballing was also used. Data was analysed using framework analysis to explore the experiences and perspectives of PwD, informal carers and HSCPs (including pharmacists) in regards to medication management in PwD and the role of community pharmacists in supporting PwD to manage their medication. Additionally, Interpretative Phenomenological Analysis (IPA) of the experiences of eight informal carers living with someone with dementia was conducted to understand how informal carers make sense of their individuality and their lived experiences of dementia, medication management and relationships with healthcare professionals.

Results

Thirty-two participants (11 informal carers; 5 PwD; 16 HSCPs [4 GPs, 5 nurses, 3 paid carers, 4 community pharmacists]) were recruited. Three key themes were identified:

1. Informal carers and PwD described the key challenges experienced by PwD and their informal carers in relation to medication management. The caring role commonly included responsibility for medication management which created both practical problems and an emotional burden. Informal carers reported that, the characteristics of dementia increased the challenge associated with managing medication. Informal carers found the process complex particularly if they were managing their own medication as well. This burden was worsened by any difficulty in obtaining appropriate support from HSCPs and if the PwD was taking a complex regimen.

2. Informal carers, PwD and HSCPs shared valuable perspectives about the process of medication management in PwD dwelling in the community. The process could be improved by co-ordinated and on-going support from HSCPs with clear communication about medication. This support should focus on the informal carer. Medication reviews, particularly when conducted in the home environment, could have a potentially positive impact on medication management.

3. Pharmacists were thought to be underutilised, and informal carers and HSCPs identified how community pharmacists could support medication management to a greater extent. Pharmacists needed to promote their services and work within a multi-disciplinary environment with full access to medical records. There was also a need for named pharmacists specially trained in dementia care and for pharmacists to work outside the pharmacy; for example conduct medication reviews in the person's own home.

Discussion

Medication management in PwD in the community is frequently very complex and needs to be improved. As dementia develops medication management becomes the responsibility of informal carers, who frequently have little or no experience or knowledge. Informal carers found this role challenging particularly when the person lacks an understanding of the need for medication. This challenge was compounded by, at times, limited support from HSCPs.

There was general agreement that PwD living in the community would benefit from more active support from community pharmacists. This support should include education delivered within the

pharmacy and more practical aspects such as going into people's houses to help them organise the medication and develop strategies to avoid medication errors. Barriers to an expanded role included the difficulty accessing pharmacy services partly due to the current funding model. Community pharmacists would also need full access to appropriate medical records and work within a multi-disciplinary framework.

Implications for practice

HSCPs need to have a clear understanding of the potential challenges that PwD and their informal carers face every day in relation to medication management; these challenges are often hidden behind the front door. Pharmacists should focus on developing their role outside the physical environment of their community pharmacy.

Research Implications

Future research needs to build a robust base of evidence on community pharmacy and how services from community pharmacy can be improved in terms of quality and patient-centered approach. From this enhanced evidence-base a complex intervention should be developed in line with Medical Research Council (MRC) guidelines. Further research is also needed on the challenges faced by people from BME communities.

Conclusion

Medication management for PwD living in the community appears to be a complex process with informal carers playing a key role. Community pharmacists could improve the process by providing further support to informal carers.

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 carers' 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 (HSCPs) 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

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 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). Eight studies were included in this meta-synthesis.

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 institutions 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 HSCPs 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 of 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 HSCPs, 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 HSCPs (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;

- Do not receive any sort of payment for this role (excluding receipt of carers' allowance).

Health and social 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 Interpretative phenomenological analysis (IPA) of the experiences of eight informal carers living with someone with dementia (37) was conducted. 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 for this report. 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 HSCPs shared valuable perspectives about the process of medication management in PwD dwelling in the community and how it could be improved. Lastly, participants (informal carers and HSCPs) 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

Half of the carers interviewed reported that they had no 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 mentioned 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 - pp2*). 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 HSCPs 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 T, 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 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.

4.2.1. Focusing on HSCPs to improve medication management in PwD

Many HSCPs (including pharmacists and GPs) and informal carers interviewed identified that the support given by HSCPs to PwD could be improved. Initially, early intervention and continued provision of support by HSCPs 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 HSCPs, 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)

HSCPs 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 HSCPs, 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)

HSCPs identified that a co-ordinated response involving several HSCPs, 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, HSCPs (especially nurses and GPs) mentioned 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, HSCPs need to co-ordinate any review and share relevant information:

"Well, unfortunately, when the GPs do home visits (...) they don't have the time to sometimes provide the patient that they've got because they've got other home visits to go to. So, 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 HSCPs 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 HSCPs 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 HSCPs (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 one 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 HSCPs, 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)

Lastly, one informal carer emphasised her desire to see an improvement on the patient information leaflet that comes with the tablets. According to this carer the printing is too small and *"you need a magnifying glass as well as your glasses to read it."* (Informal carer – pp1)

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

The majority of the HSCPs 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 HSCPs, 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, and when supporting someone with impaired cognition and it is vital that doctor's *"listen to the concerns of the relatives."* (Informal carer – pp14)

4.3. The role of the pharmacists

4.3.1. Barriers to community pharmacy

HSCPs 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 pharmacists in terms of the supply of medication:

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

HSCPs (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 HSCPs believe that pharmacists are still under-utilised. In fact, several non-pharmacists HSCPs 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 - pp5)

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 in terms of medication to all 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 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...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 HSCPs (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 patient's, 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). 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 (15,17,42,43). 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 (42). 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 (15,17,42). 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 HSCPs. As found in the past (15,42), sometimes HSCPs 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 (42) 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 (43).

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 (42).

Although there are studies exploring the role of the community pharmacist in medication management (25,44-51), 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 (23,42). 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 (6,25,51-53), 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. 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 (54). Furthermore, current funding only supports MURs, which are not full clinical reviews and focus on adherence to medication (55). Access was identified as a barrier in another study which investigated the medication management concerns of ethnic minority informal carers of PwD (42). This study found that even if the person can access the pharmacy, the physical layout of the store may inhibit interaction (42). 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 unaware of the potential role of community pharmacists in medication management including the availability of MURs (43,56,57). 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 (25,49,58). 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; at the beginning of February 2016, over 380 pharmacies had access (59). 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 (60).

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 (61). It was highlighted by several HSCPs that training pharmacists in dementia would produce positive outcomes not only to PwD and their carers but also to other HSCPs. Involving pharmacists in the clinical loop of treatment, and allowing them to have a more collaborative approach to dementia care is essential. 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 HSCPs (6,25,49).

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 (62,63). 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. HSCPs interviewed also agreed that PwD and informal carers would benefit from having more information about medication and more frequent advice on treatment (64). 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 (49,50,65) – similar conclusions were drawn from another study in people with hypertension (66). 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.

The Department of Health gives paramount importance to developing 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

This research enables HSCPs 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 the benefit and potential role more effectively to the general public.

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 these services can be improved in terms of quality and patient-centered approach. This research should be set around the MRC framework for developing a complex intervention (67). 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 (42,68), this study also alerts for 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 (25,49,58). 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 one in the field using a triangulation of perspectives from different HSCPs, 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 HSCPs interviewed and the setting in which the study was undertaken (64). 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.

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

Health Services Research and Pharmacy Practice Conference/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. *Article submitted to British Journal of Health Psychology*

Maidment ID, Aston L, Moutela T, Hilton A. The Role of Community Pharmacists in supporting people with dementia manage their medication: a qualitative study. *Article in draft – target journal – BMJ Quality and Safety*

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: to be discussed with PRUK.

Targeted mail outs to stakeholders and any associated literature: to be discussed with PRUK.

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

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.

Acknowledgements

We acknowledge the support of Alpa Patel (AP), Research Governance & Projects Manager, Aston Health Research & Innovation Cluster (AHRIC), who supported the qualitative analysis and provided guidance to Tiago Moutela. Also to all the informal carers, PwD and HSCPs who were interviewed and Hadar Zaman for his support with arranging the interviews in Yorkshire.

Appendices

A. References/Bibliography

1. World Health Organisation (WHO). 2016. Dementia – fact sheet. Available on: <http://www.who.int/mediacentre/factsheets/fs362/en/> (accessed on 1st July 2016).
2. Alzheimer's Disease International. 2009. World Alzheimer Report 2009. Available on: <https://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf> (accessed on 1st December 2015).
3. Department of Health. 2008. Living well with dementia: A National Dementia Strategy. London. Department of Health. Available on: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf (accessed on 2nd December 2015).
4. Department of Health. 2015. Policy paper 2010 to 2015 government policy: dementia. Updated 8 May 2015. London. Department of Health. Available on: <https://www.gov.uk/government/publications/2010-to-2015-government-policy-dementia/2010-to-2015-government-policy-dementia> (accessed on 1st July 2016).
5. Gómez-Pavón J, González GP, Francés RI et al. 2010. Recommendations for the prevention of adverse drug reactions in older adults with dementia. *Rev Esp Geriatr Gerontol*, 45, 89-96.
6. Maidment ID. 2013. Medication-related adverse events in older people with dementia: causes and possible solutions (Doctoral thesis, Aston University, Birmingham, UK).
7. While C, Duane F, Beanland C et al. 2012. Medication management: The perspectives of people with dementia and family carers. *Dementia*, 12, 734-750.
8. Insel K, Morrow D, Brewer B et al. 2006. Executive function, working memory, and medication adherence among older adults. *Journal of Gerontology series B: Psychological Sciences*, 61, 102–107.
9. Maidment ID, Haw C, Stubbs J et al. 2008. Medication Errors in Older People with mental health problems: a review. *Int J Geriatr Psychiatry*, 23, 564-73.
10. Schubert CC, Boustani M, Callahan CM et al. 2006. Comorbidity profile of dementia patients in primary care: Are they sicker? *J Am Geriatr Soc*, 54, 104-9.
11. Cotrell V, Wild K, Bader T. 2006. Medication management and adherence among cognitively impaired older adults. *J Gerontol Soc Work*, 47, 31-46.
12. Arlt S, Lindner R, Rosler A et al. 2008. Adherence to medication in patients with dementia. *Drugs Aging*, 25, 1033-1047.
13. Thorpe CT, Kennelty KA, Gellad WF et al. 2012. The impact of family caregivers on potentially inappropriate medication use in noninstitutionalized older adults with dementia. *Am J Geriatr Pharmacotherapy*, 10, 230-41.
14. Maddigan SL, Farris KB, Keating N et al. 2003. Predictors of Older Adults' Capacity for Medication Management in a Self-Medication Program: a retrospective chart review. *J Aging Health*, 15, 332-52.

15. Smith F, Francis SA, Gray N et al. 2003. A multi-centre survey among informal carers who manage medication for older care recipients: problems experienced and development services. *Health & Social care in the community*, 11, 138-145.
16. Francis SA, Smith F, Gray N et al. 2002. The roles of informal carers in the management of medication for older-care recipients. *Int J Pharm Pract*, 3, 1-10.
17. Francis S.A., Smith F., Gray N., & Denham M. (2006) Partnerships between older people and their carers in the management of medication. *International Journal of Older People Nursing*, 1, 201–207.
18. Maidment ID, Fox C, Boustani M et al. 2011. Medication management – the missing link in dementia interventions. *Int J Geriatr Psychiatry*, 27, 439-442.
19. Mountain GA, Craig CL. 2012. What should be in a self-management programme for people with early dementia. *Aging Ment Health*, 16, 576-83.
20. Gort AM, Mingot M, Gomez X et al. 2007. Use of the Zarit scale for assessing caregiver burden and collapse in caregiving at home in dementias. *Int J Geriatr Psychiatry*, 22, 957-62.
21. Lieto JM, Schmidt KS. 2005. Reduced ability to self-administer medication is associated with assisted living placement in a continuing care retirement community. *J Am Med Dir Assoc*, 6, 246-9.
22. Poland F, Mapes S, Pinnock H et al. 2014. Perspectives of carers on medication management in dementia: lessons from collaboratively developing a research proposal. *BMC Research Notes*, 7, 1-10.
23. Gillespie R, Mullan J, Harrison L. 2013. Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature. *Journal of Clinical Nursing*, 23, 3296–3308.
24. Bardet J, Vo T, Bedouch P et al. 2015. Physicians and community pharmacists collaboration in primary care: A review of specific models. *Research in Social Administrative Pharmacy*, 11, 602-622.
25. Maidment ID, Aston L, Hilton A et al. 2016. The role of community pharmacy in the use of antipsychotics for behavioural and psychological symptoms of dementia (BPSD): a qualitative study. *BMJ Open*.
26. Mansoor SM, Krass I, Costa DSJ et al. 2015. Factors influencing the provision of adherence support by community pharmacists: A structural equation modelling approach. *Research in Social & Administrative Pharmacy*, 769-783.
27. Mossialos E, Courtin E, Naci H et al. 2015. From “retailers” to health care providers: Transforming the role of community pharmacists in chronic disease. *Health Policy*, 119, 628-639.
28. Smith J, Picton C, Dayan M. 2013. NOW OR NEVER: shaping pharmacy for the future - the report of the Commission on future models of care delivered through pharmacy. *Royal Pharmaceutical Society*.
29. Department of Health. 2008. Pharmacy in England Building strengths – delivering the future. Available on: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228858/7341.pdf (accessed on 3rd of February 2016)
30. Parliamentary office of Science and Technology. 2005. Changing role of pharmacy. Available on: <http://www.parliament.uk/documents/post/postpn246.pdf>. (Accessed on 3rd of February 2016)

31. Alzheimer's Society / James Lind Alliance. 2013. Dementia Priority Setting Partnership. Available on: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1804 (accessed on 25th December 2015)
32. 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. *Article submitted British Journal of Health Psychology*
33. Pluye P, Hong QN. 2014. Combining the power of stories and the power of numbers: mixed methods research and mixed studies reviews. *Annual Review of Public Health, 35, 29-45.*
34. Maidment ID, Aston L, Moutela T, Hilton A. The Role of Community Pharmacists in supporting people with dementia manage their medication: a qualitative study. *Article in draft – target journal – BMJ Quality and Safety*
35. Ritchie J, Spencer L. 1994. Qualitative data analysis for applied policy research. In A. Bryman & R.G. Burgess (Eds), *Analyzing Qualitative Data*. (Pp. 310-328). London: Routledge
36. Ritchie J, Lewis J. (2003) *Qualitative Research Practice: A guide for Social Science students and researchers*. London: SAGE publications Ltd.
37. 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.*
38. Shaw R. 2010. Interpretative phenomenological analysis. In M.A. Forrester (Ed.), *Doing qualitative research in psychology a practical guide* (Pp. 177-201). London: SAGE.
39. Smith JA, Osborn M. 2008. Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative Psychology a practical guide to research methods* (2nd ed. Pp. 53 – 80). London: SAGE.
40. Willig C. 2008. *Introducing Qualitative Research in Psychology*. Maidenhead: Open University Press.
41. Travis SS, Bethea LS, Winn P. 2000. Medication administration hassles reported by family caregivers of dependent elderly persons. *The Journal of Gerontology, 55, 412-417.*
42. Gillespie RJ, Harrison L, Mullan J. 2013. Medication management concerns of ethnic minority family caregivers of people living with dementia. *Dementia, 14, 47-63*
43. Orlu-Gul M, Raimi-Abraham B, Jamieson E et al. 2013. Public engagement workshop: How to improve medicines for older people? *International Journal of Pharmaceutics, 459, 65-69.*
44. Barry HE, Parsons C, Passmore AP et al. 2013. Community pharmacists and people with dementia: a cross sectional survey exploring experiences, attitudes, and knowledge of pain and its management, *Int J Geriatr Psychiatry, 10, 1077-1085.*
45. Community Pharmacy Medicines Management Project Evaluation Team (2007). The MEDMAN study: a randomized controlled trial of community-led medicines management for patients with coronary heart disease. *Fam Pract, 24, 189-200.*

46. Holland R, Desborough J, Goodyer L et al. 2007. Does pharmacist-led medication review help to reduce hospital admissions and deaths in older people? A systematic review and meta-analysis. *Br J Clin Pharmacol*, 65, 303-316
47. Patterson S, Cadogan CA, Kerse N et al. 2014. Interventions to improve the appropriate use of polypharmacy for older people. *Cochrane Library*, 1-119.
48. Lenaghan E, Holland R, Brooks A. 2007. Home-based medication review in a high risk elderly population in primary care--the POLYMED randomised controlled trial. *Age Ageing*, 36, 292-297.
49. RESPECT trial team (2010). Cost-effectiveness of shared pharmaceutical care for older patients: RESPECT trial findings. *Br J Gen Pract*, e20-e27.
50. Wong I, Champion P, Coulton S et al. 2004. Pharmaceutical care for elderly patients shared between community pharmacists and general practitioners: a randomised evaluation. RESPECT (Randomised Evaluation of Shared Prescribing for Elderly people in the Community over Time). *BMC Health Services Research*, 4, 1-14.
51. Royal Pharmaceutical Society. 2014. Pharmacists and GP's surgeries. Available on: <http://www.rpharms.com/policy-pdfs/pharmacists-and-gp-surgeries.pdf> (accessed on 1st March 2016).
52. Royal Pharmaceutical Society. 2014. The Right Prescription: A Call to Action Reducing the inappropriate use of antipsychotic drugs for people with dementia. Available on: <http://www.rpharms.com/support-pdfs/the-right-prescription.pdf> (accessed on 1st February 2016).
53. Alzheimer's Society. 2011. Optimising treatment and care for people with behavioural and psychological symptoms of dementia. A best practice guide for health and social care professionals. Available on: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1133 (accessed on 1st September 2015).
54. Pharmaceutical Services Negotiating Committee. 2013. Guidance on the Medicines Use Review service. Available on: <http://www.nhsemployers.org/~media/Employers/Documents/Primary%20care%20contracts/Pharmacy/MUR%20Guidance.pdf> (accessed on 1st March 2016).
55. Clyne W, Blenkinsopp A, Seal R. 2008. A guide to Medication Review. National Prescribing Centre. Available on: <http://www.cff.org.br/userfiles/> (accessed 11 July 2016).
56. Gidman W, Ward P, McGregor L. 2012. Understanding public trust in services provided by community pharmacists relative to those provided by general practitioners: a qualitative study. *BMJ Open*. Doi: 10.1136/bmjopen-2012-000939.
57. Gidman W, Cowley J. 2013. A qualitative exploration of opinions on the community pharmacists' role amongst the general public in Scotland. *Int J Pharm Pract*, 21:288-96.
58. Salter C. 2010. Compliance and concordance during domiciliary medication review involving pharmacists and older people. *Sociology of Health & Illness*, 32, 21-36.
59. Pharmaceutical Services Negotiating Committee. 2016. Summary Care Records rollout: Update. Available on <http://psnc.org.uk/our-news/summary-care-records-rollout-update/> (accessed 17th April 2016)

60. Royal Pharmaceutical Society. 2015. Summary Care Records A QUICK REFERENCE GUIDE. Available on: <http://www.rpharms.com/support-pdfs/summary-care-records%28scr%29.pdf> (accessed on 19th March 2016)
61. Cooper JA, Cadogan CA, Hughes CM et al. 2015. Interventions to improve the appropriate use of polypharmacy in older people: a Cochrane Systematic Review. *BMJ Open*, 5, e009235
62. Royal College of General Practitioners. 2015. Pharmacists set to work in GP surgeries in radical move to ease pressures on general practice and improve patient care. Available on <http://www.rcgp.org.uk/news/2015/march/pharmacists-set-to-work-in-gp-surgeries.aspx> (accessed on 18th February 2016).
63. NHS England. 2015. More than 400 pharmacists to be recruited to GP surgeries by next year. Available on <https://www.england.nhs.uk/2015/11/pharmacists-recruited> (access on 17th February 2016).
64. Maxwell JA. 2013. *Qualitative research design an interactive approach*. 3rd ed. Thousand Oaks SA:SAGE
65. Avery AJ, Rodgers S, Cantrill JA et al. 2012. A pharmacists-led information technology intervention for medication errors (PINCER): a multicentre, cluster randomised, controlled trial and cost effectiveness analysis. *Lancet*, 379, 1310-1319.
66. West R, Isom M. 2014. Management of patients with hypertension: general practice and community pharmacy working together. *Br J Gen Pract*, 64, 477-478.
67. Medical Research Council. 2008. Developing and evaluating complex interventions: new guidance. Available on: <http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC004871> (accessed 27th March 2016).
68. Iliffe S, Manthorpe J. 2004. The debate on ethnicity and dementia: from category fallacy to person-centred care? *Aging and Mental health*, 8, 283-292.

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

Appendix D – Meta-synthesis paper

Exploring the evidence base for how people with dementia manage their medication in the community: a mixed studies review

Abstract

Objectives: To explore and appraise published literature that investigates: medication management in People with Dementia (PwD) who live in the community; the effect managing the medication of care-recipients has on informal carers; and the role healthcare professionals play in supporting PwD to manage medication.

Method: A mixed studies review was conducted. Web of Knowledge, Pubmed and Cochrane Library were searched post-1999 for studies about PwD that explored medication management. Data from included studies were synthesised using a convergent synthesis approach and analysed thematically.

Results: Eight studies were included that explored how PwD manage medication. Due to the nature of the disease, the additional responsibilities informal carers have and the lack of understanding of the importance of managing medication, adherence was affected.

Discussion: This review has identified non-adherence to medication in PwD and highlighted the complex task of managing medication for PwD and their informal carers. The need to understand the prescribed medication and the benefits of taking it, as well as support from healthcare professionals was shown to be important to both PwD and their informal carers. The findings warrant the need for healthcare professionals to undergo further training in understanding the difficulty in medication management for PwD.

Keywords: dementia; medication-management; community; informal carers; healthcare professionals

Introduction

Dementia has an estimated global prevalence of over 35 million people (Alzheimer's report, 2013] and affects over 800,000 in the United Kingdom (UK) (Alzheimer's Research, 2014). As the disease progresses, PwD are at risk of developing medication related problems and becoming non-adherent to prescribed regimens (Lau, Mercaldo & Weintraub, 2011; Maidment, 2013; Maidment et al., 2008). This can be caused by a number of factors, such as inadequate knowledge regarding medication, which may result in incorrect doses or administering the treatment at an inappropriate time of the day (Erien et al., 2013). Additionally, issues with medication can occur if an individual exceeds the required amount or if mistakes are made in the prescribing, dispensing or administration process (Erien et al., 2013; National patient safety agency, 2007). The risks associated with medication can proliferate if the PwD is on a complex medication regimen due to co-morbid conditions (Erien et al., 2013).

Medication optimisation aims to deliver a person-centred approach for the most safe and effective use of medication to ensure the best possible outcome for the patient (NICE, 2015). This requires the involvement of several crucial players; these include the PwD, the informal carer and often multiple health and social care professionals (While, Duane, Beanland & Koch, 2012). To date, little research has investigated the tripartite relationship of the PwD, their informal carer and healthcare professionals' impact on medication management.

With this in mind, this review aimed to explore and evaluate published literature on how PwD manage medication whilst living in the community in order to gain understanding of what is known about the effect of managing care-recipients' medication on informal carers (family or friends with an unpaid caring role). Additionally, the way in which healthcare professionals support medication optimisation in PwD and their informal caregivers will be explored.

Method

A mixed studies review methodology was adopted, which enabled the consideration of contextual factors in the investigation of medication management in PwD (Pluye, 2011).

Data Sources

PubMed, Web of Science and Cochrane Library were searched in November 2014 with restrictions to English and post 1999. Searches were updated in April 2015 and January 2016.

Search strategy

Keywords and phrases were paired with search terms relating to context. The full search strategy is included in Figure 1. LA conducted the search and evaluated potentially relevant articles to include in this review. The list of identified studies was independently assessed by TM. Any disagreements about inclusion were discussed and resolved by consensus.

Inclusion criteria

Studies included were: set in the community, in the homes of people with dementia; measured or evaluated medication management; used any method including randomised controlled trials, intervention studies, and studies using quantitative and/or qualitative data.

Critical appraisal

LA, AH and TM independently assessed study quality of the included papers using the Mixed Methods Appraisal Tool (MMAT) (Pluye, 2011). This tool is purposely designed to appraise the methodological quality of the studies included in a systematic mixed studies review (Pluye, 2011). LA, AH and TM discussed the quality ratings of the included studies based on the MMAT and agreed on the final quality score for each.

Data Extraction and Synthesis

A convergent synthesis approach was adopted using thematic analysis (Pluye, 2014). This involved the development of a matrix that comprised of all reported themes and descriptive summaries from the included papers; a cross-comparison between the themes was conducted where themes were coded and commonalities explored. The data extraction and synthesis of qualitative papers was carried out through themes or categories and author commentaries from included papers being copied verbatim into a spreadsheet. When synthesising quantitative and mixed methods papers, descriptive extractions of numerical data, some of which were presented in tables or figures, were written and added to the spreadsheet together with author commentary. LA conducted the initial analyses and examined the emergent themes. LA and IM discussed and further developed the emergent themes and agreed the final set.

Results

Study selection

The search yielded 600 references, which were screened in accordance to the inclusion criteria (see Figure 2). This was followed by reference chaining of those studies included. Papers were screened by title and then abstract. Searches were re-run five months after initial search with one further study being identified and included; one final re-run of searches took place nine months later with no additional papers included. In the final set of papers, three papers focused on medication management in PwD and informal carers (McKenzie, Bowen, Keys & Bulat, 2013; Smith, Grijseels, Ryan & Tobiansky, 2015; While et al., 2007), two papers focused purely on informal carers (Gillespie, Harrison & Mullan, 2015; Poland et al., 2014), one solely on PwD (Fiss, Thyrian, Fendrich, van den Berg, & Hoffmann, 2013), one combining PwD, informal carers and healthcare professionals (Kaasalainen et al., 2011) and one paper assessed community pharmacists (Barry, Parsons, Passmore & Hughes, 2013). Eight studies were included in the review (see Table 1).

Study quality

The appraisal of the included studies showed a variation in their quality (see Table 1 and the supplementary file for full appraisal details). Consideration for contextual influences and researchers' influence on the research conduct was lacking (Gillespie et al., 2015; Kaasalainen et al., 2011; Smith et al., 2015; While et al., 2007). One paper failed to provide a response rate (Fiss et al., 2013).

Study characteristics

Five studies used qualitative methods (Gillespie et al., 2015; Kaasalainen et al., 2011; Smith et al., 2015; Poland et al., 2014), two used quantitative methods (Fiss et al., 2013; Barry et al., 2013). and one used a mixed methods design (McKenzie et al., 2013). Three studies were conducted in the UK and Northern Ireland (Poland et al., 2014; Smith et al., 2015, Barry et al., 2013), two in Australia (Gillespie et al., 2015; While et al., 2007), one in the USA (McKenzie et al., 2013), one in Canada (Kaasalainen et al., 2011) and one in Germany (Fiss et al., 2013) (see Table 1). Studies were categorised by medication management for analysis.

Synthesis

The results of included studies generated the subsequent themes: Effects of dementia on medication management; Adherence aids; Understanding medication; Healthcare professionals' understanding of medication management in PwD.

1.1 Effects of dementia on medication management

The determination of PwD to continue to manage their own medication was found in (Gillespie et al., 2015; Kaasalainen et al., 2011; Smith et al., 2015; While et al., 2007). PwD wanted to *“develop and maintain an ability to remember their regime”* (Smith et al., 2015, author, p.739) and some informal carers appeared to support their autonomy (Gillespie et al., 2015). However, due to the progressive nature of dementia, PwD’s ability to remember to take and manage their medication was an issue that was commented upon (Gillespie et al., 2015; Kaasalainen et al., 2011; Fiss et al., 2013; While et al., 2007). *“At first she was taking them every time and then it sort of degraded... She was getting worse as time was going on* (While et al., 2007 carer, p.740).

Some PwD recognised a change in their own cognitive ability to manage their medication which seemed to cause them distress: *“He was very defiant about the fact that he had taken his medication and then he was very embarrassed when he found he hadn’t...”* (While et al., 2007, carer, p.741). However, others seemed more accepting of their informal carers being involved: *“Well my family need to know all about it... Because there is no point telling me, so they have to know everything”* (Smith et al., 2015, PwD, p.46) thus presenting a difference in coping strategies.

The nature of the disease increased the chance of non-adherence to medication (While et al., 2007; Gillespie et al., 2015; Barry et al., 2013) and one study found PwD received more support with drug administration compared to those without dementia *“dementia: 72.0%; no dementia: 36.8%”* (Fiss et al., 2013, author, p.173). An increased risk in non-adherence to medication occurred even when PwD have informal carers present (Barry et al., 2013; Fiss et al., 2013).

1.2 Adherence aids

Informal carers commented that adherence packs that were made up by their pharmacist, helped in the early stages of dementia or had worked for a time but as the disease progressed and further cognitive decline occurred, these aids became less helpful (Gillespie et al., 2015)

In order to help reduce non-adherence, one study implemented a safe home programme where informal carers of PwD were provided with a medication organiser device if the care-recipient were on a complex medication regime (>7 medications) (McKenzie et al., 2013). This device could be set to give alarms to provide an alert to the informal carers when medication was due. Informal carers found this device useful as it gave them *“...the ability to set up a month’s supply of medicine...”* (McKenzie et al., 2013, author, p.351).

Some studies found PwD presented a resistance to change and utilise medication aids as they did not want to form a new routine: *“My sister and I, we discussed eventually we will arrange blister packs for her but she really*

doesn't want to do that... she likes things the way she's always done them" (Gillespie et al., 2015, carer, p.53). Interventions should take into account the many transitions that PwD and their informal carers have to go through. The desire of PwD to hold on to something that is known although it may be more difficult was found to sometimes be preferable, reflecting a need for control in organising the medication themselves (Smith et al., 2015).

1.3 Understanding medication

Linked to theme 1.1, informal carers commented that some of their care-recipients no longer understood the importance of taking medication, which in turn led to non-adherence. *"My husband he remembers, he takes his own medication what [sic] he like but he only takes the blood pressure tablets because the other tablets he thinks do not do anything to him so it's no worth to take it* (Gillespie et al., 2015), carer, p.51).

A number of papers found that informal carers sought to understand the key aspects of their care-recipient's medication (Gillespie et al., 2015; Poland et al., 2014; Smith et al., 2015). Many informal carers across the studies discussed how they actively sought information about medicines and their side effects (Gillespie et al., 2015; Poland et al., 2014; Smith et al., 2015). *"They (informal carers) described reading package information, researching on the internet, magazines, telephone calls to a doctor and two carers had access to a BNF (British National Formulary)"* (Smith et al., 2015, author, p.47).

One study found that informal carers wanted healthcare professionals to provide them with a *"checklist"* which presents basic information in plain language regarding the medication that their care-recipients were taking; this should include *"...their (medication) effects, side effects and usage instructions..."* (Poland et al., 2014, author, p.5). This suggests understanding more about medication is valuable to informal carers, and in turn may help to encourage medication optimisation.

1.4 Healthcare professionals' understanding of medication management in PwD

Barry et al. (2013) sent questionnaires to pharmacists working in Belfast enquiring about their involvement with PwD, and specifically their knowledge about the management of pain in this population. They found that: *"...nearly all respondents (91.2%) had provided pharmaceutical care to PwD living in their own homes"* (Barry et al., 2013, author, p.1080) and most commonly would support the PwD's informal carers. However, findings suggest that pharmacists showed uncertainty in treating PwD, in regards to assessing and treating pain. This was highlighted in the: *"large proportion of respondents who chose to 'neither agree nor disagree' with certain statements"* (Barry et al., 2013, author, p.1084). The majority of pharmacists had not received any recent training in dementia (95.6%), suggesting a potential lack of awareness in how to best serve PwD. Respondents also showed a lack of knowledge surrounding the struggles that PwD may have with their medication, for example swallowing oral dosage forms (Barry et al., 2013).

Informal carers made further comments about healthcare professionals: *"Don't forget that the clinician and*

pharmacist can have little or no understanding of the practicalities” (Poland et al., 2014, carer, p.3). As well as this, comments were made about the lack of time GPs provided PwD and their carers: *“I have no good contact with my mother’s GP. I cannot reach her normally, only by receptionist or by post”* (Smith et al., 2015, carer, p.48).

Nevertheless, some informal carers valued the partnership of healthcare professionals and themselves: *“If I didn’t have the relationship with the GP that I do, mum wouldn’t be at home; she’d be in a nursing home because I wouldn’t cope”* (While et al., 2007, Carer p.745). As well as this, values were placed on the collaborative partnership between healthcare professionals working together: *“The ideal was when the GP and pharmacist would work collaboratively...”* (While et al., 2007, carer p.741).

Discussion

The review has identified a small research base that has assessed how PwD and their informal carers manage medication whilst in the community. It has also identified experiences of this population with healthcare professionals. With increasing cognitive impairment, medication management transfers to the responsibility of informal carers and there is an increased risk of non-adherence (Maidment, 2013). Adherence aids were one strategy used to support safe medication management with varying degrees of effectiveness. Informal carers need to understand the medication that the person they care for is taking. In addition, collaborative partnerships between informal carers and healthcare professionals were found to be valuable by the caregivers. The role played by informal carers and family members within the care of older adults (and other groups) has been formally recognised in the UK with the publication of new guidance for patient- and family-centred care (see for example: The King’s Fund Patient and Family-Centred Care Toolkit for healthcare providers) (The King’s Fund, 2016). Furthermore, it demonstrates that the lessons that have been learned from adopting a patient-centred approach in individual care now need to be extended to the family level because of their crucial role in care and medication management among PwD (Dahlberg, Todres & Galvin, 2009).

The results demonstrate that the medication management responsibilities passed to informal carers of PwD was a significant burden. Studies focusing on the informal carer have highlighted that they carry out their responsibilities through “trial and error” due to the lack of prior knowledge or experience in the role (Lin, Macmillan & Brown, 2011; Mastel-Smith & Stanley-Hermanns, 2012). Travis, Bethea and Win (2000) conducted a study looking at informal caregivers administering medication to dependent elderly individuals. They found that the caregiver role was affected by the balancing of work and other informal responsibilities, especially if medication had to be taken at certain times (Travis, Bethea & Winn, 2000). Smith et al. (2003) found that the maintenance of continuous supplies of medication, especially when

informal carers have work commitments was a challenge, alongside the difficulty in making clinical judgements if the care recipient was showing side effects from the medication. This was shown to be linked to informal carers struggling with interpreting information about the medication on the package inserts (Smith et al., 2003).

Interventions targeted at providing education regarding caregiving and medication management appear to be a sound basis for increased adherence. Maddigan, Farris, Keating, Wien and Johnson (2003) found that teaching the care-recipient about medication could help with adherence. However, any intervention should not just focus on adherence, but also consider whether the medication is required (*BMJ* 2005;330:293 <http://www.bmj.com/content/330/7486/293>). Additionally, interventions targeted at educating informal carers should take into account the practical issues that this population face and support medication optimisation rather than solely focusing on adherence. Banning (2009) looked at the preferred learning methods of informal carers in developing the skills of a caregiver, initiated workshops where informal carers could meet each other. However, some informal carers could not leave their care-recipient unattended so could not attend the workshop. Educating informal carers through the use of an internet resource was seen as an easily accessible and convenient tool for informal carers. However, not all informal carers may have the technological skills to use the internet (Mastel-Smith & Stanley-Hermanns, 2012). Additionally, informal carers valued the chance to ask questions, which may not be able to take place through an online medium and is an important consideration when designing an intervention to support medication management.

As noted in the results, it is highly important for healthcare professionals to understand the involvement of informal carers to PwD, and to assist them in managing their medication (Maidment, 2013). Carers involved in one study had experienced technological errors with a prescription ordering system at their GP surgery, which lead to inaccuracies with their medication (Smith et al., 2003). It is questionable as to whether a PwD who lives by themselves would pick up on these medication inaccuracies, or indeed whether all informal carers would (Banning, 2009).

It is important that appropriately trained healthcare professionals conduct regular medication reviews and ensure that their patients who have dementia are on the most straightforward routine available for them, where there are no or very few rules in terms of timings (Arlt, Lindner, Rosler & von Renteln-Kruse, 2008; Banning, 2009). Telephone-counselling services with pharmacists, educational programmes and follow-up visits, have been shown to be valuable in augmenting adherence to medication (Banning, 2009). Results from research warrant the need for healthcare professionals to be trained in the responsibilities that informal carers face in looking after someone with dementia (Gillespie, Mullan & Harrison, 2013; Lin et al., 2011; Maidment, Fox, Boustani & Katona, 2012). If this occurred, healthcare professionals may be more aware of the difficulties that informal carers face in managing PwD's medication and tailor support to aid medication optimisation including appropriate adherence.

Limitations

This review identified a relatively small number of studies, which demonstrates a lack of research conducted in the field. Some studies were appraised as poorer quality due to unmentioned consideration in methods used. The results of this mixed studies review should be interpreted with caution due to the limitations of the included studies. In spite of this, it should be noted that this review has brought together the current evidence and highlighted the areas that require additional focus through higher quality research. This should include a move towards a more detailed understanding of how PwD and their carers organise their medication.

Conclusion

This mixed studies review has highlighted concerns in medication management in PwD and the risk of non-adherence even when supported by an informal carer and the utilisation of adherence aids. The next steps should involve further qualitative work in order to understand more about how PwD and their carers organise their medication; any non-adherence issues; as well as understanding their relationships with healthcare professionals and the level of support they require from them. Also, greater understanding is required regarding the support from healthcare professionals that patients would benefit from, whether that would be information from the community pharmacist and the organisation of medication, or other interventions such as medication review. Simultaneously to this, it would be beneficial to hear from a range of healthcare professionals, and understand their role in helping PwD manage their medication, the extent to which they see PwD making medication errors and the current strategies in place to aid safe and effective medication management by PwD and/or their informal carers.

Ethical statement

Ethical approval was not required for this piece of work as it involved no data collection with humans.

Competing interests

There are no competing interests.

Funding

This report is independent research commissioned by Pharmacy Research UK. The views expressed in this publication are those of the authors and not necessarily those of Pharmacy Research UK.

References

- Alzheimer's Disease International. (2013). *World Alzheimer's report 2013 Journey of Caring: An Analysis of long-term care for dementia*. Retrieved from:
<http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf> (accessed 17th June 2015)
- Alzheimer's Research UK. (2014). *Dementia Statistics*. Retrieved from:
<http://www.alzheimersresearchuk.org/dementia-statistics/?gclid=COeXpKXM-b8CFcsJwwodJVsaRQ>
(accessed 17th June 2015)
- Arlt, S., Lindner, R., Rosler, A., & von Renteln-Kruse, W. (2008). Adherence to medication in patients with dementia. *Drugs & Aging*; 25(12): 1033-1047.
- Banning, M. (2009). A review of interventions used to improve adherence to medication in older people. *International Journal of Nursing studies*, 46, 1505-1515.
- *Barry, H.E., Parsons, C., Passmore, P.A., & Hughes, C.M. (2013). Community pharmacists and people with dementia: a cross-sectional survey exploring experiences, attitudes, and knowledge of pain and its management. *Geriatric Psychiatry*, 28, 1077-1085
- Dahlberg, K., Todres, L. & Galvin, K. (2009). Lifeworld-led care is more than patient-led care: the need for an existential theory of well-being. *Medicine, Healthcare & Philosophy*, 12, 265-271.
- Erien, J.A., Lingler, J., Sereika, S.M., Tamres, L.K., Beth, M., & Tang, F. (2013). Characterising caregiver mediated medication management in patients with memory loss. *Journal of Gerontological Nursing* 39(4), 30-39.
- Fiss, T., Thyrian, J.R., Fendrich, K., van den Berg, N., & Hoffmann, W. (2013). Cognitive impairment in primary ambulatory health care: pharmacotherapy and the use of potentially inappropriate medicine. *Geriatric Psychiatry*, 28, 173-181.
- *Gillespie, R.J., Harrison, L., & Mullan, J. (2015). Medication management concerns of ethnic minority family caregivers of people living with dementia. *Dementia*, 14(1), 47-62.
- Gillespie, R., Mullan, J., & Harrison, L. (2013). Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature. *Journal of Clinical Nursing*, 23, 3296-3308.
- *Kaasalainen, S., Dolovich, L., Papaioannou, A. et al. (2011). The process of medication management for older adults with dementia. *Journal of Nursing and Healthcare of Chronic Illness*; 3, 407-418.

Lau, D.T., Mercaldo, N.D., & Weintraub, S. (2011). Functional decline associated with polypharmacy and potentially inappropriate medications in community-dwelling older adults with dementia. *American journal of alzheimer's disease and other dementias*, 26(8), 606-615.

Lin, M.C., Macmillan, M., & Brown, N. (2011). A grounded theory longitudinal study of carers' experiences of caring for people with dementia. *Dementia*, 11(2), 181-197.

Maddigan, S.L., Farris, K.B., Keating, N., Wien, C.A., & Johnson, J.A. (2003). Predictors of older adults' capacity for medication management in a self-medication program: a retrospective chart review. *Journal of Aging and Health*, 15(2), 332-352.

Maidment, I.D. (2013) Medication-related adverse events in older people with dementia: causes and possible solutions (Doctoral thesis, Aston University, Birmingham, UK).

Maidment, I., Fox, C., Boustani, M., & Katona, C. (2012). Medication management- the missing link in dementia interventions. *International Journal of Geriatric Psychiatry*, 27(5), 439-442.

Maidment, I.D., Haw, C., Stubbs, J., Fox, C., Katona, C., & Franklin, B.D. (2008). Medication errors in older people with mental health problems: a review. *International Journal of Geriatric Psychiatry*, 23, 564-573.

Mastel-Smith, B., & Stanley-Hermanns, M. (2012). "It's like we're grasping at anything": caregivers' education needs and preferred learning methods. *Qualitative Health Research*, 22(7), 1007-1015.

*McKenzie, B., Bowen, M.E., Keys, K., & Bulat, T. (2013). Safe home program: a suite of technologies to support extended home care of persons with dementia. *American Journal of Alzheimer's Disease and other Dementias*, 28(4), 348-354.

National Patient Safety Agency. National Reporting and Learning System. *Safety in doses – improving the use of medicines in the NHS. Learning from National Reporting 2007*. Retrieved from:

<http://www.nrls.npsa.nhs.uk/resources/?entryid45=61625> (accessed 17th June 2015)

NICE Guideline. Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes (2015). Retrieved from: www.nice.org.uk/guidance/ng5/resources/medicines-optimisation-the-safe-and-effective-use-of-medicines-to-enable-the-best-possible-outcomes-51041805253 (accessed 11th May 2016).

Pluye P, Robert E, Cargo M, Bartlett G, O'Cathain A, Griffiths F, Boardman F, Gagnon MP, Rousseau MC.

Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. Retrieved on 17th June

2015 from <http://mixedmethodsappraisaltoolpublic.pbworks.com> 2011; Archived by WebCite® at

<http://www.webcitation.org/5tTRTc9yJ>

Pluye P, Hong QN. (2014). Combining the power of stories and the power of numbers: mixed methods research and mixed studies reviews. *Annual Review of Public Health, 35*, 29-45.

*Poland, F., Mapes, S., Pinnock, H. et al. (2014). Perspective of carers on mediation management in dementia: lessons from collaboratively developing a research proposal. *BMC Research Notes, 7*: 463.

Pope C, Mays N, Popay J. *Synthesizing qualitative and quantitative health evidence: a guide to methods*. Maidenhead: Open University Press; 2007.

Primary Care Does home based medication review keep older people out of hospital? The HOMER randomised controlled trial *BMJ*2005; 330 doi: <http://dx.doi.org/10.1136/bmj.38338.674583.AE>(Published 03 February 2005).

*Smith, F., Grijseels, M.S., Ryan, P., & Tobiansky, R. (2015). Assisting people with dementia with their medicines: experiences of family carers. *International Journal of Pharmacy Practice, 23*, 44-51.

Smith, F., Francis, S.A., Gray, N., Denham, M., & Graffy, J. (2003). A multi-centre survey among informal carers who manage medication for older care recipients: problems experienced and development of services. *Health and Social Care in the Community, 11*(2), 138-145.

The King’s Fund (2016). Patient and Family-Centred Care Toolkit. Available from: <http://www.kingsfund.org.uk/projects/pfcc> (accessed 11/04/2016).

Travis, S.S., Bethea, L.S, & Winn, P. (2000). Medication administration hassles reported by family caregivers of dependent elderly persons. *Journal of Gerontology: Medical Sciences, 55*, 412-417.

*While, C., Duane, F., Beanland, C., & Koch, S. (2012). Medication management: the perspectives of people with dementia and family carers. *Dementia, 12*(6), 734-750.

Table 1. Search strategy.

Topic	Search terms
Medic*NEAR/4 management	“dementia” OR “alzheimer’s disease” AND “caregiver” OR “carer” OR “family carer” OR “informal carer”

Figure 2: PRISMA flowchart

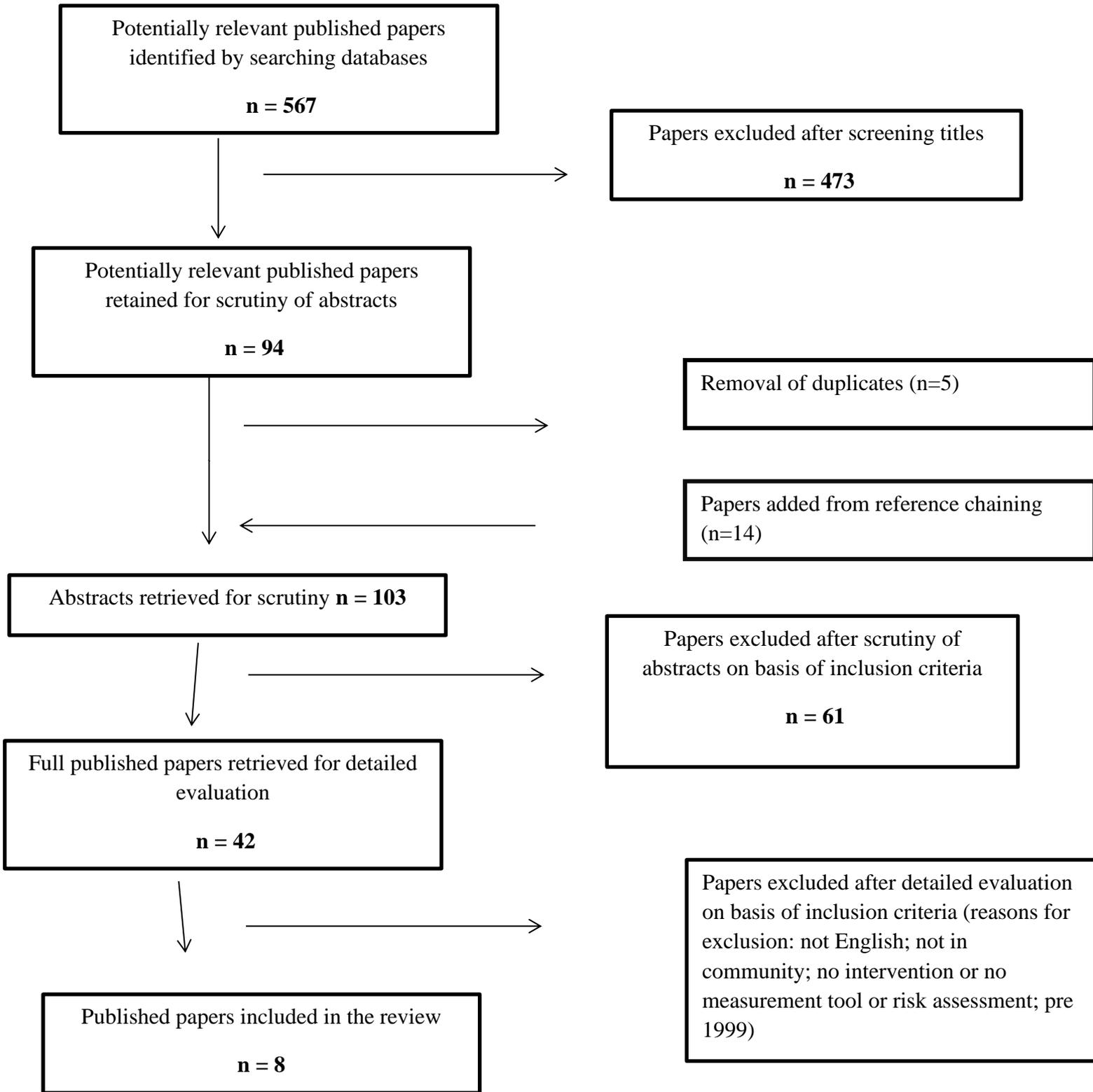


Table 1 – Characteristics of included studies

Study		Journal	Aim	Participants		Location	Data collect
Paper number	First author & date			Sampling Method	Number		
P1	Barry (2013)	International Journal of Geriatric Psychiatry, 28, 1077-1085.	To explore community pharmacists' experiences with and attitudes towards people with dementia, and to determine the knowledge they have about pain and its management in this patient population.	Purposive	Community pharmacists : 182	Northern Ireland	Questi e
P2	Fiss (2013)	International Journal of Geriatric Psychiatry, 28, 173-181.	To analyse the occurrence of Potentially Inappropriate Medication (PIM) taken by elderly individuals in the AGnES studies in primary care and to analyse the determinants for the intake of PIM in patients with	Convenience	Patients: 342	Germany	Germa PRISCU

			suspicion of dementia.				
P3	Gillespie (2015)	Dementia, 14(1), 47-62.	The study aimed to remedy this situation by exploring the views of ethnic minority informal caregivers of people living with dementia and their medication management experience including the adequacy of their access to medication management information and support.	Purposive	Caregivers: 30	Australia	Focus and individual interviews
P4	Kaasalainen (2011)	Journal of Nursing and Healthcare of Chronic Illness, 3(4), 407-418.	The purpose of this grounded theory study was to explore the personal experiences related to medication management of community-dwelling older adults diagnosed with dementia, their informal caregivers and healthcare professionals	Theoretical sampling	Community health nurses: 10 Pharmacists : 10 Informal physicians: 6 Informal caregivers: 20 PwD: 11	Canada	Interviews

			who assist them.				
P5	McKenzie (2013)	American Journal of Alzheimer's Disease & other Dementias, 28(4), 348-354.	The primary aim of this article is to report the implementation and adoption of the Safe Home Program and the caregiver assessments of these technologies and devices to determine which one may be used to support caregivers.	Purposive	Caregivers and PwD: 59	USA	Questions and interviews
P6	Poland (2014)	<i>BMC Research notes</i> , 7, 463.	The paper aims primarily to describe the PPI process which was intended to inform and validate the development of a future research proposal which could be well-informed by carers' perspectives	Purposive	Carers: 9	UK	Focus groups
P7	Smith (2014)	<i>International Journal of Pharmacy Practice</i> , 23, 44-51.	The aims of this study were to examine the scope and range of medicines related assistance provided by	Convenience	Carers: 14 Care-recipients: 5	UK	Interviews

			informal carers of people with dementia, the problems that arise and to identify how service provision could become more responsive to these needs.				
P8	While (2012)	<i>Dementia, 12(6), 734-750.</i>	This paper examines the perspectives of the person with dementia and their carers to explore if there are any significant differences in their medication management experiences when compared to older adults without dementia and their carers.	Purposive and snowballing approach	PwD: 8 Informal carers: 9	Australia	Intervi