Abstract

Dementia is fast becoming a global concern due to a demographic shift towards an older population. Many studies have shown that caring for a family member or friend has a profound and negative impact on the physical, emotional and psychosocial aspects of the caregivers’ life. One significant activity that a family caregiver undertakes is assistance with the management of medicines. This review was undertaken to ascertain what the issues are that affect optimal medicines use from the perspectives of people living with dementia and their caregivers, both in the community and care home settings. A literature search was conducted using electronic databases, employing a combination of search terms. A total of 16 studies met the inclusion criteria. Six broad themes were identified, together with some recommendations to improve medicines use in people with dementia. Challenges to medicines use centred on medicines management and administration, the impact on the caregiver and care recipient, their partnership and interface with formal care. Future research
should focus on developing targeted interventions that can overcome these challenges to achieve optimal medicines use.

**Keywords**

Dementia, medicines use, medication administration, medication management, challenge, family caregiver/carer

**1. Introduction**

Population demographics in both developed and developing countries is shifting towards a population with a higher proportion of people aged 65 years of age and above (Stegemann et al., 2010). It is predicted that by 2050, the number of people aged 60 and over will reach 1.25 billion globally (Prince et al., 2013) and in the United Kingdom (UK) 23% of the population will be 65 years of age or over by 2035 (ONS, 2012). The increase in life expectancy also means that the number of people suffering from dementia is on the rise. Alzheimer’s Disease International estimated that there are 46.8 million people living with dementia worldwide in 2015, with that number set to double every 20 years to reach 131.5 million in 2050 (Alzheimer’s Disease International, 2015).

The increase in the likelihood of acquiring chronic diseases with age and resultant polypharmacy increases the risk of non-adherence (Murray et al., 2004), with unwanted clinical and economic consequences. It is imperative that patients adhere to their treatment regimen to achieve therapeutic goals. Adherence rates in the elderly are variable; but, as the amount of medicines taken and the complexity of the regimen increases, the adherence rate potentially decreases (Miller, 2008). Furthermore, adherence and ability to manage medicines can be compromised in people with cognitive impairment (Cooper et al., 2005; Ahn et al., 2009; Allaire et al., 2009; Hayes et al., 2009). As people living with dementia (PLWD)
gradually lose their ability to manage their medicines appropriately, family members or friends step in to assist them. Family caregivers may take on a range of activities including administering medicines, managing side effects, and maintaining the medicinal supply (Francis et al., 2002; Smith et al., 2003). PLWDs’ ability to make decisions is also impaired (Hirschman et al., 2005). Consequently PLWD tend to rely heavily on their family caregivers to manage their medicines, which can sometimes create a burden and negatively impacts the caregiver’s quality of life (Francis et al., 2002; Smith et al., 2003; Slattum and Johnson, 2004; Cotrell et al., 2006; Sörensen et al., 2006; Arlt et al., 2008; Etters et al., 2008).

Safe and effective medication use is a priority for all patients, especially older patients, due to their co-morbidities and diverse needs, and this includes tailoring the drug formulations and optimising their medication management (Orwig et al., 2006; Stegemann et al., 2010). This is even more vital in PLWD due to their decline in cognitive abilities. The medication management role of family caregivers of older people and people with cognitive impairment, the tasks they take on and the factors impacting them has been explored in a recent review (Gillespie et al., 2013), but the problems and issues with medication use faced by PLWD and their caregivers were not the main focus of the paper. Optimising medication use requires a comprehensive understanding of the issues affecting medicines management and administration in practice, both in the community and care home settings.

The research question for this review was ‘What are the challenges to medicines use faced by people living with dementia and their caregivers?’ Medicines use refers to the management and administration of medicines. The term ‘caregiver’ encompasses both family caregivers and carers or nurses in care homes so that we are better able to understand the scope of issues across different care settings and level of training and in relation to people with a range of dementia severity. The review highlights the scope and range of problems experienced by PLWD and their caregivers. It focuses on problems that relate directly to medicines
management and administration, which in turn can help inform future recommendations, as well as aid in the development of targeted interventions.

2. Method

2.1. Search strategy

A literature search was conducted to identify studies relevant to the research question using bibliographic databases such as PubMed, EMBASE, International Pharmaceutical Abstracts, Scopus, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE and Science Direct. Additional searches were made using the International Journal of Pharmacy Practice (IJPP) abstracts and Google (Google was used as an additional tool to identify any studies that may have been missed in the database search). No time limit restrictions were imposed when conducting the search; all databases were searched from time of inception until January 2015. In addition, the references from the retrieved studies were manually searched for any other relevant studies. The following search terms were used:


2.2. Eligibility criteria

Studies that provided either the PLWD, their caregiver’s or both of their perspectives on challenges to medication use were deemed eligible. There were no restrictions on method type; studies that used qualitative, quantitative or a mix of both qualitative and quantitative methods were included. The term ‘caregiver’ encompassed both family caregivers and carers or nurses in care homes (nursing or residential). Family caregivers were defined as family
members or friends who provided unpaid medication assistance to PLWD. Abstracts of posters were also included as they provide information on ongoing work that is being conducted in this area, as there is limited published data available. Studies were excluded if they did not mention whether people had a form of cognitive impairment, or if they were not written in the English language. Table 1 shows the eligibility criteria used.

**2.3. Data extraction and analysis**

Information relating to problems encountered with medication management and administration to PLWD, as well as recommendations and suggestions to improve medication use were extracted from the articles. Information regarding the study design and setting, type and number of participants, sampling and recruitment, and methodology was also recorded on a data extraction sheet, which was developed by and reviewed within the research team. Regular meetings of the research team were held to discuss findings and a team approach was undertaken to the reviewing of papers. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to appraise the qualitative studies (Tong et al., 2007). Appraisal of qualitative and quantitative studies involved an assessment of the research methods, study design and sampling. The first author (DA) conducted initial thematic analysis using an inductive approach when reading the articles to generate themes; challenges and factors impacting medicines use were extracted and recoded into themes. All authors met regularly to discuss and review emerging themes and to reach consensus on the final analysis findings.
3. Results

3.1. Search results

The total of 2657 citations were retrieved from searching the databases. A search using Google UK and Google Australia yielded 4 further studies that also met the inclusion criteria, bringing the total number to 2661. The titles of all citations were reviewed and 2378 studies were excluded. The abstracts and full text of the remaining 283 citations were then reviewed according to the inclusion criteria, and 270 were excluded for the following reasons: duplicates (n=64), irrelevant (n=206). An examination of the full text of the remaining 13 papers confirmed that they fulfilled the eligibility criteria. After a manual search of the reference lists and citations of the retrieved articles, 3 further studies were deemed relevant. Figure 1 represents a flowchart of the literature review process.

The literature review yielded 16 studies that reported issues with medicines use by PLWD and caregivers. The participants in twelve of the studies were either PLWD, their caregivers or both (Hutchings et al., 2010; Taylor and Weiss, 2010; Kaasalainen et al., 2011; Carder, 2012; Jansen et al., 2012; While et al., 2012; De Witt Jansen et al., 2013; Erlen et al., 2013; Maidment et al., 2013; Poland et al., 2014; Gillespie et al., 2015; Smith et al., 2015). Participants in the other four studies were older people in general, some of whom had dementia or who were caregivers of PLWD (Travis et al., 2000; Lau et al., 2009; Reinhard et al., 2012; Mirk et al., 2013). Six of the studies were conducted in the United States of America (USA), seven in the UK, one in Canada, and two in Australia. All of the studies were conducted fairly recently, with the earliest published in 2000 and the latest published early in 2015. Thirteen studies used qualitative methods, two adopted a mixed methods approach, and one used quantitative methods. Tables 2 and 3 provide the characteristics of the retrieved studies.
Six major themes were generated from the 16 relevant studies; organisation and scheduling logistics, administration procedures and health literacy, impact on caregiver, impact on PLWD, partnership between caregiver and PLWD, and how this partnership interfaces with formal care. Each theme had sub-themes that clarified how each one affects medicines use in PLWD and their caregivers; these are shown in table 4.

3.2. Quality of studies

The quality of reporting varied in the qualitative studies; some criteria were not reported at all, such as the presence of nonparticipants in interviews/focus groups, while others were consistently reported such as methodology, sampling and reporting of findings. Some of the studies utilised more than one method of data collection, which strengthened the study findings and provided a more flexible method to accommodate participants (Travis et al., 2000; Hutchings et al., 2010; Carder, 2012; Maidment et al., 2013; Gillespie et al., 2015). Some of the studies included were conference abstracts and therefore limited information was available in regard to methodology and sampling (Taylor and Weiss, 2010; Jansen et al., 2012; De Witt Jansen et al., 2013; Maidment et al., 2013; Mirk et al., 2013).

3.3. Theme 1: organisation and scheduling logistics

This theme describes the issues encountered by caregivers with their medication management tasks and the skills required by them to effectively and safely manage medicines for the PLWD. One of the major barriers faced by caregivers and patients, as highlighted in most studies, was difficulties in obtaining medicines, such as filling prescriptions, and maintaining regular supplies of medicines at home (Travis et al., 2000; Lau et al., 2009; Mirk et al., 2013; Taylor and Weiss, 2010; Gillespie et al., 2015; Smith et al., 2015). Managing medications was a challenging task and necessitated various activities such as ordering and collecting...
prescriptions and/or supplies from various sources, sometimes using different procedures, which complicated the task further (Smith et al., 2015).

Caregivers also felt that Scheduling logistics was a daily stress, with the most common challenge being the ability to arrange their own medication schedule to correspond with that of the patient’s (Travis et al., 2000; While et al., 2012). There is also the added challenge of fitting both medication schedules alongside the caregiver’s routine. Polypharmacy and complex medication regimens can complicate this task further as caregivers stated they faced difficulties in monitoring when prescriptions needed to be filled, and in maintaining sufficient amounts of medications at home.

Managing multiple medications and the procurement and maintenance of medicine stock at home were all highlighted by caregivers as a barrier to the medicines use process. Caregivers developed strategies, such as keeping a diary to aid medicines management (Smith et al., 2015) or putting stickers on prescriptions to remind them to renew them (While et al., 2012), to overcome these challenges and to ensure that medicines were available for the PLWD and were given in a timely manner.

3.4. Theme 2: administration procedures and health literacy

This theme encompasses a variety of concerns in regards to information relating to the medicines and their administration from the perspectives of both the caregiver and the PLWD. All of the studies included in the literature review discussed issues relating to this theme.

Poland et al. (2014) obtained the views of both caregivers of PLWD and HCPs on medication management and the challenges encountered. They found that simple tasks, such as preparing Fybogel™ laxative by suspending granules in water for oral administration, can become
complicated and cause distress to the caregiver and delay medicine administration; one
caregiver stated that the formulation sets too quickly to be swallowed by the patient. This
highlighted the impracticality of some medicines. Difficulties in administration of medicines
can cause caregivers to modify formulations without consulting HCPs thus risking the safety
and efficacy of medicines (Erlen et al., 2013; Mirk et al., 2013; Gillespie et al., 2015).
Tailored formulations need to be prescribed to PLWD to aid the administration process, such
as prescribing liquids to patients with swallowing difficulties (Kaasalainen et al., 2011). In
the study by Travis et al. (2000), 32% of caregivers’ accounts related to difficulties in
administration of medicines; caregivers of PLWD experienced more stress than those of other
caregivers. This was due to this patient groups’ cognitive decline and behavioural problems
which can potentially make medicine administration a challenging task (Travis et al., 2000;
Kaasalainen et al., 2011; De Witt Jansen et al., 2013). Other more general issues identified
were complicated instructions, such as how to give medicines, and making decisions on when
to withhold or give medicines, especially those which are Pro Re Nata (PRN).
Knowledge concerning medicines was also an important issue that affected caregivers’
decisions regarding administration (Lau et al., 2009; While et al., 2012; Maidment et al.,
2013; Poland et al., 2014; Gillespie et al., 2015; Smith et al., 2015). Caregivers of PLWD
highlighted the importance of patient information leaflets, but still faced difficulties in
making judgements regarding medicines use (Smith et al., 2015). One study demonstrated the
importance of caregivers being aware of dosages in case of labelling errors, (Taylor and
Weiss, 2010). Poor vision and manual dexterity were other barriers to medicines use (While
et al., 2012; Mirk et al., 2013; Gillespie et al., 2015). A complex medicine regimen with four
or more medicines, doses that required adjustment by the caregiver and a variety of dosage
forms to be administered can also be a barrier to optimum medicines use, increasing
caregiver stress (Kaasalainen et al., 2011; Reinhard et al., 2012; Maidment et al., 2013; Mirk
et al., 2013; Gillespie et al., 2015). Some caregivers stated that they had to develop strategies to overcome some of these challenges, such as the use of multi compartment compliance aids, reminders, or placing medicines near their bed (Hutchings et al., 2010; Kaasalainen et al., 2011; While et al., 2012; Gillespie et al., 2015; Smith et al., 2015). Some of the strategies adopted by caregivers were not always safe and effective, as found by Gillespie et al., (2015) where caregivers placed medications for the PLWD in unlabelled easy-to-open containers to assist the PLWD in overcoming their dexterity problems and to maintain their independence.

One study focused on the factors affecting the decision to administer PRN medicines to residents with dementia by paid carers in care homes (Carder, 2012) and found that the decision process can be a complicated one, influenced by various issues. PLWD were not always able to verbalise their need for a certain medication, such as for pain relief. The med aide would have to know the patient very well to be able to successfully interpret their request by studying their behaviour and nonverbal cues. De Witt Jansen et al., (2013) conducted their study at nursing homes to explore the experiences of staff in administering medicines to dementia patients. The authors found several barriers to the medication management and administration procedures that could either be attributed to factors relating to the PLWD or factors relating to the work environment. Disease severity, cognitive capacity, physical disability and difficult behaviours were all barriers. Environment-related factors included interruptions by colleagues or the PLWD’s family members, distractions and the ratio of staff to residents. Staff members all agreed that the solution to overcoming barriers to medicine administration at nursing homes was effective communication with everyone involved; the residents, their relatives and the HCPs. This was also found in Carder’s (2012) study.
3.5. Theme 3: impact on caregiver

Caregivers can sometimes feel ill-prepared for the role they have taken on (Maidment et al., 2013; Poland et al., 2014). Taking on this role and managing medicines can disturb their daily routine and affect what activities they can take part in, especially if they do not live with the PLWD (Hutchings et al., 2010; Reinhard et al., 2012; Smith et al., 2015). Furthermore, it can cause them anxiety when they cannot cope with the pressures involved in this role; this may make them feel that they are inadequately supporting the care recipient (Poland et al., 2014).

Caregivers’ concerns regarding the PLWD changed along the progression of dementia. At the mild stage caregivers focused on starting anti-dementia medications and acquiring information regarding the condition (Jansen et al., 2012). As the condition progressed to the moderate-severe stage, caregivers were more anxious about the issues they faced with the administration of medicines and how to make adherence easier. At this stage, the burden of caregiving was more evident. The role they adopted with medication assistance also changed as the PLWD’s cognitive abilities deteriorated. At the early stages of the condition, they may take on a minor role with managing medications such as requesting blister packs to be made by the pharmacist (Gillespie et al., 2015). At the moderate to severe stages, the caregiver takes on a much greater role and develops strategies for safe and effective medication use.

Staff administering medications to PLWD at care homes stated that the skills required to care for people with dementia differed from other residents; for example, there was a need to be more patient and empathetic (De Witt Jansen et al., 2013). When PLWD start refusing medications, staff members had to make ethical judgments on administration of medicines, and felt that the pharmacist was the best source of assistance in this case. Caregiving staff at care homes identified the need for more efficient training concerning medication administration to dementia patients, such as the appropriateness and acceptability of available...
formulations for PLWD and effective pain management. They also expressed a need to rely on their skills in understanding each individual resident to better care for them (Carder, 2012; De Witt Jansen et al., 2013).

Managing and administering medicines has a direct impact on the caregiver. The responsibility involved in managing medicines negatively affects the caregivers’ quality of life, restricting their time and activities elsewhere, thus causing carer burden (Jansen et al., 2012; While et al., 2012; Gillespie et al., 2015; Smith et al., 2015). This role has been taken on by friends or family members; it was deemed a personal responsibility by themselves, by PLWD, or by society (Reinhard et al., 2012). Family carers may take on this role without any form of support and without prior knowledge of what the role involves (Reinhard et al., 2012; While et al., 2012). Some caregivers stated that they were not provided with any information about the prescribed medicines. Furthermore, no support or information regarding medicines use, such as medication use reviews, was offered to them by their pharmacist (Taylor and Weiss, 2010). Carers feel that they can only depend on themselves and any past experiences that may assist them; in fact, caregivers become so engrossed in the role that they are reluctant to have someone else take on the responsibility of the PLWD’s medicines (While et al., 2012; Smith et al., 2015). However, this was not always the case, as some caregivers were relieved when other family members assisted in managing medications or finding information on medicines (Gillespie et al., 2015).

3.6. Theme 4: impact on PLWD

The PLWD is central to any discussion on challenges to medicines management; the caregiver may be responsible for managing the medicines but the PLWD is profoundly affected by the process. PLWD and their caregivers all stress the importance of the PLWD retaining their independence and autonomy (Kaasalainen et al., 2011; Poland et al., 2014;
This can have a positive effect on PWLD taking their medicines as they still feel in control of at least one aspect of their lives.

The PLWD’s cognitive abilities and severity of dementia have a strong influence on how they take their medications. One study illustrated how PLWD dealt with medicine management as their disease progressed (Kaasalainen et al., 2011). PLWD can sometimes refuse to take medicines when they are distressed or confused due to their disease. At the early stages, they may refuse because they do not want to relinquish control over their lives (While et al., 2012), or because they believe that what they are experiencing is a normal part of the aging process (Gillespie et al., 2015). This can lead to anxiety over their loss of independence. As the dementia progresses, their reasons for refusing to take medications change to delusional beliefs and paranoia of being poisoned, challenging behaviours or believing that they do not require these medicines (While et al., 2012; Gillespie et al., 2015). People at the severe and end stages of the condition were found to be mostly compliant, but their challenges to medicine taking were now due to difficulties remembering how to take medicines or swallowing them (De Witt Jansen et al., 2013). In addition, any changes to their environment or transition in their care may have a drastic effect on their abilities to manage and take their medicines (While et al., 2012).

### 3.7. Theme 5: partnership between caregiver and PLWD

The partnership between the caregiver and the PLWD is crucial to medicines use. Some caregivers feel they need to empower the PLWD by allowing them to feel more in control of their medicines, and this strengthens the relationship between the two parties (Poland et al., 2014). Caregivers need to be vigilant to discern when PLWD need help, as their transition from self-management to caregiver-led management is often variable and difficult to predict (While et al., 2012). This constant task of assessing the PLWD’s capabilities to manage and
take their own medicines has been described as very taxing by some caregivers (Gillespie et al., 2015). Some of the signs that might indicate that the caregiver needs to provide assistance with medicines includes the PLWD forgetting to refill prescriptions, forgetting when and how to take the medications and forgetting the information given to them by their GP or pharmacist (Gillespie et al., 2015). Administration of some medicines can also pose some problems; some dosage forms can cause discomfort when being administered, such as suppositories, inflicting stress on the caregiver and affecting their relationship with the care recipient.

The transition process impacts both the PLWD and their caregiver; the PLWD is either reluctant to release their autonomy or welcomes the assistance, and the caregiver needs to make the transition as easy and smooth as possible (While et al., 2012). Caregivers have to balance their efforts at allowing the PLWD to retain their autonomy, such as involving the PLWD in information and decisions about their medicines, with their feelings of anxiety at doing so (Smith et al., 2015).

Gillespie et al., (2015) found that some caregivers did not trust the PLWD to manage and take their medications as instructed and always had to be vigilant. Trust is required between both, especially when the PLWD is transitioning from self-management to caregiver-led management. The relationship needs to be transparent, with both parties working together to ensure that medicines are being taken in a safe and effective way.

**3.8. Theme 6: interface with formal care**

This theme describes the relationship between HCPs, such as GPs, pharmacists and staff at care homes, and the caregiver-PLWD dyad. Some caregivers felt that HCPs do not fully comprehend the role that caregivers have taken on and the burden and stress involved with it (Poland et al., 2014). This can lead to caregivers not sharing their medication-related
concerns, thereby increasing their burden (Lau et al., 2009). Furthermore, caregivers felt they were not being involved by the GP in discussions and decisions about the PLWD’s medication, such as when medications were changed or new ones prescribed (Jansen et al., 2012; Gillespie et al., 2015; Smith et al., 2015). The opposite also occurs, where the GP completely disregards the care-recipient in the consultation and talks directly to the caregiver, causing distress to the PLWD (Smith et al., 2015). There is also the issue of the limited consultation time, causing some caregivers not to voice their concerns or ask for more information, as well as the inaccessibility of some HCPs (Smith et al., 2015).

Gillespie et al., (2015) explored caregivers’ views from ethnic minority groups in Australia regarding support from HCPs. Some caregivers voiced their contentment with their relationship with their HCPs, sometimes relying on them to advise and mediate, as the PLWD respects them and would comply with their instructions. Not all caregivers had access to a pharmacist who provided assistance, even when the pharmacist was aware that a person had dementia.

A strong relationship between the caregiver-PLWD dyad and HCPs where communication is invited is necessary to facilitate medicines management (Kaasalainen et al., 2011). Caregiver and patient support, such as education, should also be provided, to ease the hassles involved with the management of medicines and ensure both the caregiver and PLWD are confident in their roles (Kaasalainen et al., 2011). Both PLWD and their caregivers value their relationship with their HCPs and its continuity; they need to trust the HCPs to be able to depend on them (While et al., 2012).

3.9. Recommendations to improve medicines use in PLWD

The studies all provided recommendations for improvements from the participants, the authors or both. Most studies emphasised the importance of promoting communication
between the PLWD and their caregiver, between them and HCPs, and between HCPs themselves (Lau et al., 2009; Kaasalainen et al., 2011; Jansen et al., 2012; Reinhard et al., 2012; While et al., 2012; De Witt Jansen et al., 2013; Poland et al., 2014; Gillespie et al., 2015; Smith et al., 2015). Better communication can assist in building trust and shed light on the problems experienced to allow them to be addressed appropriately. In addition, involving both the caregiver and the PLWD in decisions was also seen as a way to overcome barriers and encourage them to voice their concerns so that HCPs are made aware of any medication hassles experienced. Furthermore, *HCPs need to be more accessible to caregivers and the PLWD*. Communication problems and inaccessibility of HCPs have been cited elsewhere as problems faced by PLWD/older people and their caregivers (Bruce et al., 2002; Francis et al., 2006; Prorok et al., 2013).

The *provision of clear information* regarding medicines is vital (Travis et al., 2000; Hutchings et al., 2010; Kaasalainen et al., 2011; Reinhard et al., 2012; While et al., 2012; Erlen et al., 2013; Gillespie et al., 2015; Smith et al., 2015). This can be given to caregivers and PLWD orally or written during consultations, by the pharmacist when dispensing the medicines and through education. Information should be specific to each person and should include what the medicines are, what they do, the dose to be given, the best ways to administer the medicine, side effects that may be experienced and if any changes have been made to the medicine.

Another recommendation was to *deliver tailored support and training and better services* that meet the needs of caregivers and PLWD (Lau et al., 2009; Hutchings et al., 2010; Taylor and Weiss, 2010; Kaasalainen et al., 2011; Carder, 2012; Reinhard et al., 2012; While et al., 2012; De Witt Jansen et al., 2013; Erlen et al., 2013; Mirk et al., 2013; Poland et al., 2014; Gillespie et al., 2015). Training and support should focus on improving medication management and administration skills, especially regarding PLWD refusal to take the
medicine, the modification of medicines to improve patient acceptability and dosage adjustment. Support and services should be well publicised for them to be utilised by PLWD and their caregivers. Training should be tailored to each stage of dementia, and repeated from time to time so that information and skills are retained. Furthermore, training on the best ways of administering medicines and the different dosage forms available should also be given to care home staff to optimise the acceptability for the PLWD.

*Medication reviews by pharmacists* were welcomed by caregivers and PLWD as a way to receive tailored advice and information, as well as a means to relay any medication-related hassles they may be experiencing. Pharmacist-led medication reviews have been shown to improve adherence and medicine knowledge in older people (Holland et al., 2008). Strategies employed by caregivers and PLWD to ease medication management include the use of reminders and a variety of compliance aids, such as dosette boxes. These should be assessed by the HCP to ensure the caregiver and/or care recipient are able to use them and find them helpful. It was also suggested that *doctors should re-evaluate prescriptions* to assess the need for medicines, simplify regimens and improve dosage forms, such as switching a patient from a solid to liquid formulation when swallowing difficulties were present.

4. Discussion

This review has shown that some data is available on the challenges in regard to medication management and administration in older people. However, not all studies were exclusive to a dementia population; some included a wider sample of older people, some of whom had dementia; others were caregivers of people living with dementia. Medicines use in this population may provide added difficulties for caregivers as a result of issues relating to cognitive impairment (Poland et al., 2014). There is a distinction between the care provided in the two types of care homes; this may have an implication on the findings because of the
level of training of staff members. Although six different themes and recommendations for improvement were found, there is some overlap.

*Administering medicines* was shown to be a huge component of being a caregiver of PLWD and had many difficulties associated with it (Travis et al., 2000; Reinhard et al., 2012). It is further complicated by polypharmacy, a variety of dosage forms and difficulty to interpret instructions (Maidment et al., 2013), all affecting optimal medicines use. Travis et al., (2000) demonstrated that whilst all caregivers faced difficulties when administering and managing medicines, those caring for cognitively impaired individuals experienced more difficulties. This can be attributed to the patient refusing to take medicines, causing the caregiver to get frustrated (Reinhard et al., 2012; Gillespie et al., 2015). Barriers to medicines management and administration for caregivers of PLWD were not limited to dementia-specific medicines, but to all medicines and dosage forms being administered (Poland et al., 2014). Something as simple as applying eye drops can turn into a lengthy process. Even making a decision about whether the person requires pain relief can pose difficulties as it is sometimes challenging for the PLWD to express their pain. The administration of medicines can also be hindered by the PLWD developing difficulties swallowing or forgetting how to take medicines (Smith et al., 2015; Gillespie et al., 2015).

In care homes, better communication with the healthcare team, the PLWD and their family were expressed to be essential to the administration of medicines. Furthermore, staff administering medicines in care homes had to possess certain skills to be able to understand each PLWD individually to make the process of medicine administration safe and effective (Carder, 2012; De Witt Jansen et al., 2013).

The *degree of cognitive impairment* is a major issue and affects various activities, including medicines administration and negotiating the transition from self to caregiver-led
management. While two studies attributed barriers to medicines management to dementia severity (Kaasalainen et al., 2011; Jansen et al., 2012), another study associated problems with medicines management and administration with regimen complexity rather than dementia severity (Erlen et al., 2013).

The partnership between the PLWD and their caregiver was a critical component of the medicines use process; it was seen as a continuous struggle due to issues such as the PLWD refusing to take medicines and their need to retain their independence (While et al., 2012). The transition to caregiver-led management may not go smoothly as the PLWD can resent the help offered. Also, caregivers cannot always discern at what stage the PLWD can no longer manage their medicines safely and effectively (Poland et al., 2014; Gillespie et al., 2015).

Caregivers often lacked the knowledge required to make certain decisions (While et al., 2012). The care-giving role they take on often entails making complex judgements regarding medicines use for the PLWD, adding more to their stress (Maidment et al., 2013).

Study findings also illustrated how caregivers lacked medication-related support (Travis et al., 2000; Taylor and Weiss, 2010; Poland et al., 2014; Gillespie et al., 2015; Smith et al., 2015). Family caregivers sometimes modify medicines, such as crushing tablets, or conceal them in food to ease medicine administration to those who have difficulties swallowing or refuse to take medicines. They may not realise that this can affect the therapeutic outcome, leading to lack of quality, safety and efficacy of the medicine (Gillespie et al., 2015).

General support and services aimed at PLWD and their caregivers have been highlighted as requiring improvement (National Audit Office, 2007). There is a need for improved systems regarding the provision of medicines-related information, such as the importance of the treatment, expected side effects and administration procedure, for PLWD and their caregivers to ensure optimal medicines use and adherence (While et al., 2012).
Findings emphasise the importance of maintaining a good relationship between the caregiver-PLWD dyad and HCP; effective communication and trust can assist the caregiver in coping with the pressures, thereby allowing the PLWD to be cared for at home for a longer time (While et al., 2012; Poland et al., 2014).

The literature also highlights the role that HCPs could play in overcoming some of the issues through better communication, inclusion of both PLWD and their caregivers in discussions and decisions, and provision of detailed and individualised medication information. The role of the pharmacist was stressed as being integral to this. Pharmacists are an accessible and approachable source of information and support in the community. Pharmacists can also have a major role in care homes by supplying advice to nurses and carers on medication administration and dosage forms, as well as reviewing medicines. Older people have been shown to benefit from pharmacist-led interventions (Ryan et al., 2014). There is a need for consistency in the advice and reviews administered to PLWD and their caregivers to ensure there is no confusion.

Interventions to improve medicines use in PLWD have not been widely documented and have either focused on other diseases, such as diabetes, or on adherence (Ryan et al., 2014). A recent systematic review found 75 studies of interventions to improve medicines use (Ryan et al., 2014). Some studies employed one intervention, such as simplifying the medication regimen, while others offered a mixed approach, such as different forms of education. Although single interventions have been shown to improve medicine knowledge and use, the use of multiple interventions provides a broader scope. Very few interventions concentrated on skills and communication; both have been emphasised as pivotal to overcoming barriers to medicines use in the current review.
A systematic review of interventions to improve adherence in people with cognitive impairment included only 3 studies (Campbell et al., 2012). The interventions ranged from reminders and compliance aid medication boxes at the care recipients’ home, a telephone/televideo medication reminder, and refill reminder postcards and medication schedules. Findings did not show significant benefits, but a recurring message was the importance of continuous interaction and communication with PLWD.

Awareness needs to be raised regarding the common practice of modifying the original form of the medicine; caregivers should be provided with information and support to choose safe and effective alternative strategies when administering medicines. Medicine-focused training, such as the use of alternative dosage forms, was suggested as a solution to overcome barriers to the administration of medicines to residents with dementia (De Witt Jansen et al., 2013).

5. Implications for research

This review has shed light on some gaps in knowledge, which includes how PLWD and their caregivers cope with deteriorating cognitive impairment and other physical difficulties that arise due to the progression of dementia that might affect how medicines are used. Contradictory findings require further research to confirm whether the degree of cognitive impairment or regimen complexity act as a barrier to medicines use.

Future studies should also examine the implications of choice of different routes of administration and dosage forms and should endeavour to include the views of both PLWD and their caregivers. Recommendations can then be given to achieve patient-centric care regarding effective medicines use for PLWD. Healthcare professionals also need to understand the importance of asking about how medicines are being taken or given to ensure they are being adhered to and administered safely and effectively, leading to acceptability both for PLWD and their caregiver. There is also a need for better education and support.
provision, and future research should focus on interventions with a wider scope that do not focus on adherence but on the medication use process to improve medicines use for this population. In order for interventions to be successful, the needs of PLWD and their caregivers need to be taken into account when developing them (Brodaty and Donkin, 2009).

6. Limitations

This review does not include many studies, but this may be attributed to the specificity of the research question. Furthermore, this highlights that this topic may not be well-researched. Some of the findings included were from conference abstracts; although the findings may not always be as comprehensively peer-reviewed as journal articles, they widen the scope of the issues. Many of the studies had small sample sizes; this can be due to the qualitative methods used and the difficulty in recruiting PLWD and their caregivers (Hutchings et al., 2010; Goodman et al., 2011).

7. Conclusion

Dementia is a debilitating syndrome that affects both the patient and their caregiver, and the number of people suffering from it will steadily increase as the population is ageing. Although much work has been done to raise awareness of dementia, the focus has been on its diagnosis and management. Medication use may be a minor aspect of the disease but, if overlooked, can negatively affect management of the condition. The challenges associated with medicines use in PLWD should be addressed and should include the perspectives of all those involved: the PLWD, their family caregiver and their HCP. Studying challenges to medicines use along the progression of dementia can assist in developing targeted interventions to improve medicines management for this patient population.
References


Hirschman, K.B., Joyce, C.M., James, B.D., Xie, S.X., Karlawish, J.H.T., 2005. Do Alzheimer’s disease patients want to participate in a treatment decision, and would their caregivers let them? The Gerontologist 45, 381–388.


Figure 1: Literature review process flowchart
<table>
<thead>
<tr>
<th>Eligibility criteria</th>
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</thead>
<tbody>
<tr>
<td>Qualitative, quantitative, or mixed-methods</td>
</tr>
<tr>
<td>Perspective of PLWD, caregiver, or both</td>
</tr>
<tr>
<td>Caregivers included family caregivers and carers or nurses from care homes</td>
</tr>
<tr>
<td>States that patients have form of dementia</td>
</tr>
<tr>
<td>In the English language</td>
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<tr>
<td>Author</td>
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<tr>
<td>Travis et al.</td>
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<tr>
<td>Lau et al.</td>
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<tr>
<td>Hutchings et al.</td>
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<td>Taylor and Weiss</td>
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<tr>
<td>Kaasalainen et al.</td>
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<td>Author</td>
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<tr>
<td>Jansen et al. (2012)</td>
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<td>While et al. (2012)</td>
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<td>De Witt Jansen et al. (2013)</td>
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<td>Mirk et al. (2013)</td>
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<td>Poland et al. (2014)</td>
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<tr>
<td>Smith et al. (2015)</td>
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<td>Gillespie et al. (2015)</td>
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</tbody>
</table>
Table 3: Characteristics of studies that employed quantitative or mixed methods

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Type (number) of participants</th>
<th>Method of data collection</th>
<th>Methodology</th>
<th>Aim of the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reinhard et al. (2012)</td>
<td>USA</td>
<td>Family caregivers (1,677)</td>
<td>Online survey</td>
<td>NA</td>
<td>To learn the responsibilities of family caregivers relating to medical tasks and the difficulties encountered</td>
</tr>
<tr>
<td>Erlen et al. (2013)</td>
<td>USA</td>
<td>Family caregivers (91), PLWD (91)</td>
<td>Interviews, questionnaires, telephone follow-up</td>
<td>Not reported</td>
<td>To examine medication management deficiencies, as well as medicine taking issues, encountered by PLWD and their caregivers in the community</td>
</tr>
<tr>
<td>Maidment et al. (2013)</td>
<td>UK</td>
<td>Alzheimer’s Society Research Network Volunteers (20), family caregivers</td>
<td>Focus group, survey</td>
<td>Not reported</td>
<td>To explore the role of informal caregivers relating to safe medication management and the issues involved</td>
</tr>
<tr>
<td>Theme</td>
<td>Sub-themes</td>
<td></td>
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</tbody>
</table>
| **Organisation and scheduling Logistics**<sup>1,2,4,8,11,15,16</sup> | • Scheduling multiple medications throughout the day and giving them on time  
• Acquiring, storing, and tracking medications  
• Coordinating personal medication schedules with those of the PLWD |
| **Administration procedures and health literacy**<sup>1-6, 8-16</sup> | • Giving medication to a disoriented/difficult PLWD  
• Deciding when to hold, adjust, or discontinue a medication, especially PRN medicines  
• Learning how to administer different types of dosage forms and medicines that can be invasive or distressing  
• Having a good understanding of the medicines being given such as difference between brand and generic names  
• Employing strategies to aid medication use  
• Dealing with polypharmacy and medication complexity (number and frequency of medications)  
• Having dexterity problems, poor vision, or swallowing difficulties |
| **Impact on caregiver**<sup>1, 3-16</sup> | • Managing medications and administration impacted on caregivers’ time and lives by restricting activities and causing burden  
• Medication management described as emotionally difficult and frightening  
• Reluctance in relying on others for support  
• Difficulties accessing support to ensure safe and effective medicines use  
• Role taken with little choice, support, skills, or medication knowledge. (feelings of personal responsibility)  
• How caregivers’ concerns and feelings regarding medicines use change as dementia progresses  
• Skills/training needed by formal caregivers when dealing with PLWD |
| **Impact on PLWD**<sup>5, 8-10, 14-16</sup> | • PLWD need to retain autonomy/independence  
• PLWD refusal to take medications due to denial (early stage) or delusions (severe stage)  
• PLWD affected by transition in care and change in environment |
| **Partnership between caregiver and PLWD**<sup>8, 5, 14-16</sup> | • Trust needed between patient and caregiver  
• Transition from self-management to caregiver-led management  
• Inclusion of caregiver and PLWD in decision-making |
| **Interface with formal care**<sup>2, 5, 7, 8, 14-16</sup> | • Need to communicate effectively with HCPs about medication-related issues (communication barriers and facilitators)  
• Trust and continuity between HCPs, caregivers and PLWD  
• Accessibility of HCPs  
• Inclusion of both caregiver and PLWD in discussions and decisions |
