

1 **Challenges to optimal medicines use in people living with dementia and**
2 **their caregivers: a literature review**

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11

12 **Abstract**

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

25 should focus on developing targeted interventions that can overcome these challenges to
26 achieve optimal medicines use.

27 **Keywords**

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

30 **1. Introduction**

31 Population demographics in both developed and developing countries is shifting towards a
32 population with a higher proportion of people aged 65 years of age and above (Stegemann et
33 al., 2010). It is predicted that by 2050, the number of people aged 60 and over will reach 1.25
34 billion globally (Prince et al., 2013) and in the United Kingdom (UK) 23% of the population
35 will be 65 years of age or over by 2035 (ONS, 2012). The increase in life expectancy also
36 means that the number of people suffering from dementia is on the rise. Alzheimer's Disease
37 International estimated that there are 46.8 million people living with dementia worldwide in
38 2015, with that number set to double every 20 years to reach 131.5 million in 2050
39 (Alzheimer's Disease International, 2015).

40 The increase in the likelihood of acquiring chronic diseases with age and resultant
41 polypharmacy increases the risk of non-adherence (Murray et al., 2004), with unwanted
42 clinical and economic consequences. It is imperative that patients adhere to their treatment
43 regimen to achieve therapeutic goals. Adherence rates in the elderly are variable; but, as the
44 amount of medicines taken and the complexity of the regimen increases, the adherence rate
45 potentially decreases (Miller, 2008). Furthermore, adherence and ability to manage medicines
46 can be compromised in people with cognitive impairment (Cooper et al., 2005; Ahn et al.,
47 2009; Allaire et al., 2009; Hayes et al., 2009). As people living with dementia (PLWD)

48 gradually lose their ability to manage their medicines appropriately, family members or
49 friends step in to assist them. Family caregivers may take on a range of activities including
50 administering medicines, managing side effects, and maintaining the medicinal supply
51 (Francis et al., 2002; Smith et al., 2003). PLWDs' ability to make decisions is also impaired
52 (Hirschman et al., 2005). Consequently PLWD tend to rely heavily on their family caregivers
53 to manage their medicines, which can sometimes create a burden and negatively impacts the
54 caregiver's quality of life (Francis et al., 2002; Smith et al., 2003; Slattum and Johnson, 2004;
55 Cotrell et al., 2006; Sørensen et al., 2006; Arlt et al., 2008; Eters et al., 2008).

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

66 The research question for this review was 'What are the challenges to medicines use faced by
67 people living with dementia and their caregivers?'. Medicines use refers to the management
68 and administration of medicines. The term 'caregiver' encompasses both family caregivers
69 and carers or nurses in care homes so that we are better able to understand the scope of issues
70 across different care settings and level of training and in relation to people with a range of
71 dementia severity. The review highlights the scope and range of problems experienced by
72 PLWD and their caregivers. It focuses on problems that relate directly to medicines

73 management and administration, which in turn can help inform future recommendations, as
74 well as aid in the development of targeted interventions.

75 **2. Method**

76 ***2.1. Search strategy***

77 A literature search was conducted to identify studies relevant to the research question using
78 bibliographic databases such as PubMed, EMBASE, International Pharmaceutical Abstracts,
79 Scopus, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL),
80 MEDLINE and Science Direct. Additional searches were made using the International
81 Journal of Pharmacy Practice (IJPP) abstracts and Google (Google was used as an additional
82 tool to identify any studies that may have been missed in the database search). No time limit
83 restrictions were imposed when conducting the search; all databases were searched from time
84 of inception until January 2015. In addition, the references from the retrieved studies were
85 manually searched for any other relevant studies. The following search terms were used:
86 ‘Dementia’ OR ‘Alzheimer’s’ OR ‘Mild cognitive impairment’ AND ‘Caregiver*’ OR
87 ‘Carer*’ OR ‘Care home*’ OR ‘Carer centre*’ AND ‘Medication*’ OR ‘Prescription*’ OR
88 ‘Pharmaceutical*’ OR ‘Drug*’ OR ‘Formulation*’ OR ‘Dosage form*’ AND ‘Barrier*’ OR
89 ‘Challenge*’ AND ‘Medication administration’ OR ‘Medication management’ OR
90 ‘Medication use’.

91 ***2.2. Eligibility criteria***

92 Studies that provided either the PLWD, their caregiver’s or both of their perspectives on
93 challenges to medication use were deemed eligible. There were no restrictions on method
94 type; studies that used qualitative, quantitative or a mix of both qualitative and quantitative
95 methods were included. The term ‘caregiver’ encompassed both family caregivers and carers
96 or nurses in care homes (nursing or residential). Family caregivers were defined as family

97 members or friends who provided unpaid medication assistance to PLWD. Abstracts of
98 posters were also included as they provide information on ongoing-work that is being
99 conducted in this area, as there is limited published data available. Studies were excluded if
100 they did not mention whether people had a form of cognitive impairment, or if they were not
101 written in the English language. Table 1 shows the eligibility criteria used.

102 ***2.3.Data extraction and analysis***

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

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120 **3. Results**

121 ***3.1. Search results***

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

131 The literature review yielded 16 studies that reported issues with medicines use by PLWD
132 and caregivers. The participants in twelve of the studies were either PLWD, their caregivers
133 or both (Hutchings et al., 2010; Taylor and Weiss, 2010; Kaasalainen et al., 2011; Carder,
134 2012; Jansen et al., 2012; While et al., 2012; De Witt Jansen et al., 2013; Erlen et al., 2013;
135 Maidment et al., 2013; Poland et al., 2014; Gillespie et al., 2015; Smith et al., 2015).
136 Participants in the other four studies were older people in general, some of whom had
137 dementia or who were caregivers of PLWD (Travis et al., 2000; Lau et al., 2009; Reinhard et
138 al., 2012; Mirk et al., 2013). Six of the studies were conducted in the United States of
139 America (USA), seven in the UK, one in Canada, and two in Australia. All of the studies
140 were conducted fairly recently, with the earliest published in 2000 and the latest published
141 early in 2015. Thirteen studies used qualitative methods, two adopted a mixed methods
142 approach, and one used quantitative methods. Tables 2 and 3 provide the characteristics of
143 the retrieved studies.

144 Six major themes were generated from the 16 relevant studies; organisation and scheduling
145 logistics, administration procedures and health literacy, impact on caregiver, impact on
146 PLWD, partnership between caregiver and PLWD, and how this partnership interfaces with
147 formal care. Each theme had sub-themes that clarified how each one affects medicines use in
148 PLWD and their caregivers; these are shown in table 4.

149 ***3.2. Quality of studies***

150 The quality of reporting varied in the qualitative studies; some criteria were not reported at
151 all, such as the presence of nonparticipants in interviews/focus groups, while others were
152 consistently reported such as methodology, sampling and reporting of findings. Some of the
153 studies utilised more than one method of data collection, which strengthened the study
154 findings and provided a more flexible method to accommodate participants (Travis et al.,
155 2000; Hutchings et al., 2010; Carder, 2012; Maidment et al., 2013; Gillespie et al., 2015).
156 Some of the studies included were conference abstracts and therefore limited information was
157 available in regard to methodology and sampling (Taylor and Weiss, 2010; Jansen et al.,
158 2012; De Witt Jansen et al., 2013; Maidment et al., 2013; Mirk et al., 2013).

159 ***3.3. Theme 1: organisation and scheduling logistics***

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

167 prescriptions and/or supplies from various sources, sometimes using different procedures,
168 which complicated the task further (Smith et al., 2015).

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

176 Managing multiple medications and the procurement and maintenance of medicine stock at
177 home were all highlighted by caregivers as a barrier to the medicines use process. Caregivers
178 developed strategies, such as keeping a diary to aid medicines management (Smith et al.,
179 2015) or putting stickers on prescriptions to remind them to renew them (While et al., 2012),
180 to overcome these challenges and to ensure that medicines were available for the PLWD and
181 were given in a timely manner.

182 ***3.4.Theme 2: administration procedures and health literacy***

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

187 Poland et al. (2014) obtained the views of both caregivers of PLWD and HCPs on medication
188 management and the challenges encountered. They found that simple tasks, such as preparing
189 Fybogel™ laxative by suspending granules in water for oral administration, can become

190 complicated and cause distress to the caregiver and delay medicine administration; one
191 caregiver stated that the formulation sets too quickly to be swallowed by the patient. This
192 highlighted the impracticality of some medicines. Difficulties in administration of medicines
193 can cause caregivers to modify formulations without consulting HCPs thus risking the safety
194 and efficacy of medicines (Erlen et al., 2013; Mirk et al., 2013; Gillespie et al., 2015).
195 Tailored formulations need to be prescribed to PLWD to aid the administration process, such
196 as prescribing liquids to patients with swallowing difficulties (Kaasalainen et al., 2011). In
197 the study by Travis et al. (2000), 32% of caregivers' accounts related to difficulties in
198 administration of medicines; caregivers of PLWD experienced more stress than those of other
199 caregivers. This was due to this patient groups' cognitive decline and behavioural problems
200 which can potentially make medicine administration a challenging task (Travis et al., 2000;
201 Kaasalainen et al., 2011; De Witt Jansen et al., 2013). Other more general issues identified
202 were complicated instructions, such as how to give medicines, and making decisions on when
203 to withhold or give medicines, especially those which are Pro Re Nata (PRN).

204 Knowledge concerning medicines was also an important issue that affected caregivers'
205 decisions regarding administration (Lau et al., 2009; While et al., 2012; Maidment et al.,
206 2013; Poland et al., 2014; Gillespie et al., 2015; Smith et al., 2015). Caregivers of PLWD
207 highlighted the importance of patient information leaflets, but still faced difficulties in
208 making judgements regarding medicines use (Smith et al., 2015). One study demonstrated the
209 importance of caregivers being aware of dosages in case of labelling errors, (Taylor and
210 Weiss, 2010). Poor vision and manual dexterity were other barriers to medicines use (While
211 et al., 2012; Mirk et al., 2013; Gillespie et al., 2015). A complex medicine regimen with four
212 or more medicines, doses that required adjustment by the caregiver and a variety of dosage
213 forms to be administered can also be a barrier to optimum medicines use, increasing
214 caregiver stress (Kaasalainen et al., 2011; Reinhard et al., 2012; Maidment et al., 2013; Mirk

215 et al., 2013; Gillespie et al., 2015). Some caregivers stated that they had to develop strategies
216 to overcome some of these challenges, such as the use of multi compartment compliance aids,
217 reminders, or placing medicines near their bed (Hutchings et al., 2010; Kaasalainen et al.,
218 2011; While et al., 2012; Gillespie et al., 2015; Smith et al., 2015). Some of the strategies
219 adopted by caregivers were not always safe and effective, as found by Gillespie et al., (2015)
220 where caregivers placed medications for the PLWD in unlabelled easy-to-open containers to
221 assist the PLWD in overcoming their dexterity problems and to maintain their independence.

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

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239 *3.5.Theme 3: impact on caregiver*

240 Caregivers can sometimes feel ill-prepared for the role they have taken on (Maidment et al.,
241 2013; Poland et al., 2014). Taking on this role and managing medicines can disturb their daily
242 routine and affect what activities they can take part in, especially if they do not live with the
243 PLWD (Hutchings et al., 2010; Reinhard et al., 2012; Smith et al., 2015). Furthermore, it can
244 cause them anxiety when they cannot cope with the pressures involved in this role; this may
245 make them feel that they are inadequately supporting the care recipient (Poland et al., 2014).

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

256 Staff administering medications to PLWD at care homes stated that the skills required to care
257 for people with dementia differed from other residents; for example, there was a need to be
258 more patient and empathetic (De Witt Jansen et al., 2013). When PLWD start refusing
259 medications, staff members had to make ethical judgments on administration of medicines,
260 and felt that the pharmacist was the best source of assistance in this case. Caregiving staff at
261 care homes identified the need for more efficient training concerning medication
262 administration to dementia patients, such as the appropriateness and acceptability of available

263 formulations for PLWD and effective pain management. They also expressed a need to rely
264 on their skills in understanding each individual resident to better care for them (Carder, 2012;
265 De Witt Jansen et al., 2013).

266 Managing and administering medicines has a direct impact on the caregiver. The
267 responsibility involved in managing medicines negatively affects the caregivers' quality of
268 life, restricting their time and activities elsewhere, thus causing carer burden (Jansen et al.,
269 2012; While et al., 2012; Gillespie et al., 2015; Smith et al., 2015). This role has been taken
270 on by friends or family members; it was deemed a personal responsibility by themselves, by
271 PLWD, or by society (Reinhard et al., 2012). Family carers may take on this role without any
272 form of support and without prior knowledge of what the role involves (Reinhard et al., 2012;
273 While et al., 2012). Some caregivers stated that they were not provided with any information
274 about the prescribed medicines. Furthermore, no support or information regarding medicines
275 use, such as medication use reviews, was offered to them by their pharmacist (Taylor and
276 Weiss, 2010). Carers feel that they can only depend on themselves and any past experiences
277 that may assist them; in fact, caregivers become so engrossed in the role that they are
278 reluctant to have someone else take on the responsibility of the PLWD's medicines (While et
279 al., 2012; Smith et al., 2015). However, this was not always the case, as some caregivers were
280 relieved when other family members assisted in managing medications or finding information
281 on medicines (Gillespie et al., 2015).

282 ***3.6.Theme 4: impact on PLWD***

283 The PLWD is central to any discussion on challenges to medicines management; the
284 caregiver may be responsible for managing the medicines but the PLWD is profoundly
285 affected by the process. PLWD and their caregivers all stress the importance of the PLWD
286 retaining their independence and autonomy (Kaasalainen et al., 2011; Poland et al., 2014;

287 Gillespie et al., 2015; Smith et al., 2015). This can have a positive effect on PWLD taking
288 their medicines as they still feel in control of at least one aspect of their lives.

289 The PLWD's cognitive abilities and severity of dementia have a strong influence on how they
290 take their medications. One study illustrated how PLWD dealt with medicine management as
291 their disease progressed (Kaasalainen et al., 2011). PLWD can sometimes refuse to take
292 medicines when they are distressed or confused due to their disease. At the early stages, they
293 may refuse because they do not want to relinquish control over their lives (While et al.,
294 2012), or because they believe that what they are experiencing is a normal part of the aging
295 process (Gillespie et al., 2015). This can lead to anxiety over their loss of independence. As
296 the dementia progresses, their reasons for refusing to take medications change to delusional
297 beliefs and paranoia of being poisoned, challenging behaviours or believing that they do not
298 require these medicines (While et al., 2012; Gillespie et al., 2015). People at the severe and
299 end stages of the condition were found to be mostly compliant, but their challenges to
300 medicine taking were now due to difficulties remembering how to take medicines or
301 swallowing them (De Witt Jansen et al., 2013). In addition, any changes to their environment
302 or transition in their care may have a drastic effect on their abilities to manage and take their
303 medicines (While et al., 2012).

304 ***3.7.Theme 5: partnership between caregiver and PLWD***

305 The partnership between the caregiver and the PLWD is crucial to medicines use. Some
306 caregivers feel they need to empower the PLWD by allowing them to feel more in control of
307 their medicines, and this strengthens the relationship between the two parties (Poland et al.,
308 2014). Caregivers need to be vigilant to discern when PLWD need help, as their transition
309 from self-management to caregiver-led management is often variable and difficult to predict
310 (While et al., 2012). This constant task of assessing the PLWD's capabilities to manage and

311 take their own medicines has been described as very taxing by some caregivers (Gillespie et
312 al., 2015). Some of the signs that might indicate that the caregiver needs to provide assistance
313 with medicines includes the PLWD forgetting to refill prescriptions, forgetting when and how
314 to take the medications and forgetting the information given to them by their GP or
315 pharmacist (Gillespie et al., 2015). Administration of some medicines can also pose some
316 problems; some dosage forms can cause discomfort when being administered, such as
317 suppositories, inflicting stress on the caregiver and affecting their relationship with the care
318 recipient.

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

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

330 ***3.8.Theme 6: interface with formal care***

331 This theme describes the relationship between HCPs, such as GPs, pharmacists and staff at
332 care homes, and the caregiver-PLWD dyad. Some caregivers felt that HCPs do not fully
333 comprehend the role that caregivers have taken on and the burden and stress involved with it
334 (Poland et al., 2014). This can lead to caregivers not sharing their medication-related

335 concerns, thereby increasing their burden (Lau et al., 2009). Furthermore, caregivers felt they
336 were not being involved by the GP in discussions and decisions about the PLWD's
337 medication, such as when medications were changed or new ones prescribed (Jansen et al.,
338 2012; Gillespie et al., 2015; Smith et al., 2015). The opposite also occurs, where the GP
339 completely disregards the care-recipient in the consultation and talks directly to the caregiver,
340 causing distress to the PLWD (Smith et al., 2015). There is also the issue of the limited
341 consultation time, causing some caregivers not to voice their concerns or ask for more
342 information, as well as the inaccessibility of some HCPs (Smith et al., 2015).

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

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

356 ***3.9. Recommendations to improve medicines use in PLWD***

357 The studies all provided recommendations for improvements from the participants, the
358 authors or both. Most studies emphasised the importance of *promoting communication*

359 between the PLWD and their caregiver, between them and HCPs, and between HCPs
360 themselves (Lau et al., 2009; Kaasalainen et al., 2011; Jansen et al., 2012; Reinhard et al.,
361 2012; While et al., 2012; De Witt Jansen et al., 2013; Poland et al., 2014; Gillespie et al.,
362 2015; Smith et al., 2015). Better communication can assist in building trust and shed light on
363 the problems experienced to allow them to be addressed appropriately. In addition, involving
364 both the caregiver and the PLWD in decisions was also seen as a way to overcome barriers
365 and encourage them to voice their concerns so that HCPs are made aware of any medication
366 hassles experienced. Furthermore, *HCPs need to be more accessible to caregivers and the*
367 *PLWD*. Communication problems and inaccessibility of HCPs have been cited elsewhere as
368 problems faced by PLWD/older people and their caregivers (Bruce et al., 2002; Francis et al.,
369 2006; Prorok et al., 2013).

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

378 Another recommendation was to *deliver tailored support and training and better services* that
379 meet the needs of caregivers and PLWD (Lau et al., 2009; Hutchings et al., 2010; Taylor and
380 Weiss, 2010; Kaasalainen et al., 2011; Carder, 2012; Reinhard et al., 2012; While et al.,
381 2012; De Witt Jansen et al., 2013; Erlen et al., 2013; Mirk et al., 2013; Poland et al., 2014;
382 Gillespie et al., 2015). Training and support should focus on improving medication
383 management and administration skills, especially regarding PLWD refusal to take the

384 medicine, the modification of medicines to improve patient acceptability and dosage
385 adjustment. Support and services should be well publicised for them to be utilised by PLWD
386 and their caregivers. Training should be tailored to each stage of dementia, and repeated from
387 time to time so that information and skills are retained. Furthermore, training on the best
388 ways of administering medicines and the different dosage forms available should also be
389 given to care home staff to optimise the acceptability for the PLWD.

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

400 **4. Discussion**

401 This review has shown that some data is available on the challenges in regard to medication
402 management and administration in older people. However, not all studies were exclusive to a
403 dementia population; some included a wider sample of older people, some of whom had
404 dementia; others were caregivers of people living with dementia. Medicines use in this
405 population may provide added difficulties for caregivers as a result of issues relating to
406 cognitive impairment (Poland et al., 2014). There is a distinction between the care provided
407 in the two types of care homes; this may have an implication on the findings because of the

408 level of training of staff members. Although six different themes and recommendations for
409 improvement were found, there is some overlap.

410 *Administering medicines* was shown to be a huge component of being a caregiver of PLWD
411 and had many difficulties associated with it (Travis et al., 2000; Reinhard et al., 2012). It is
412 further complicated by polypharmacy, a variety of dosage forms and difficulty to interpret
413 instructions (Maidment et al., 2013), all affecting optimal medicines use. Travis et al., (2000)
414 demonstrated that whilst all caregivers faced difficulties when administering and managing
415 medicines, those caring for cognitively impaired individuals experienced more difficulties.
416 This can be attributed to the patient refusing to take medicines, causing the caregiver to get
417 frustrated (Reinhard et al., 2012; Gillespie et al., 2015). Barriers to medicines management
418 and administration for caregivers of PLWD were not limited to dementia-specific medicines,
419 but to all medicines and dosage forms being administered (Poland et al., 2014). Something as
420 simple as applying eye drops can turn into a lengthy process. Even making a decision about
421 whether the person requires pain relief can pose difficulties as it is sometimes challenging for
422 the PLWD to express their pain. The administration of medicines can also be hindered by the
423 PLWD developing difficulties swallowing or forgetting how to take medicines (Smith et al.,
424 2015; Gillespie et al., 2015).

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

430 The *degree of cognitive impairment* is a major issue and affects various activities, including
431 medicines administration and negotiating the transition from self to caregiver-led

432 management. While two studies attributed barriers to medicines management to dementia
433 severity (Kaasalainen et al., 2011; Jansen et al., 2012), another study associated problems
434 with medicines management and administration with regimen complexity rather than
435 dementia severity (Erlen et al., 2013).

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

442 Caregivers often lacked the *knowledge* required to make certain decisions (While et al.,
443 2012). The care-giving role they take on often entails making complex judgements regarding
444 medicines use for the PLWD, adding more to their stress (Maidment et al., 2013).

445 Study findings also illustrated how caregivers lacked medication-related *support* (Travis et
446 al., 2000; Taylor and Weiss, 2010; Poland et al., 2014; Gillespie et al., 2015; Smith et al.,
447 2015). Family caregivers sometimes modify medicines, such as crushing tablets, or conceal
448 them in food to ease medicine administration to those who have difficulties swallowing or
449 refuse to take medicines. They may not realise that this can affect the therapeutic outcome,
450 leading to lack of quality, safety and efficacy of the medicine (Gillespie et al., 2015).

451 General support and services aimed at PLWD and their caregivers have been highlighted as
452 requiring improvement (National Audit Office, 2007). There is a need for improved systems
453 regarding the provision of medicines-related information, such as the importance of the
454 treatment, expected side effects and administration procedure, for PLWD and their caregivers
455 to ensure optimal medicines use and adherence (While et al., 2012).

456 Findings emphasise the importance of *maintaining a good relationship between the*
457 *caregiver-PLWD dyad and HCP*; effective communication and trust can assist the caregiver
458 in coping with the pressures, thereby allowing the PLWD to be cared for at home for a longer
459 time (While et al., 2012; Poland et al., 2014).

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

470 *Interventions* to improve medicines use in PLWD have not been widely documented and
471 have either focused on other diseases, such as diabetes, or on adherence (Ryan et al., 2014).
472 A recent systematic review found 75 studies of interventions to improve medicines use (Ryan
473 et al., 2014). Some studies employed one intervention, such as simplifying the medication
474 regimen, while others offered a mixed approach, such as different forms of education.
475 Although single interventions have been shown to improve medicine knowledge and use, the
476 use of multiple interventions provides a broader scope. Very few interventions concentrated
477 on skills and communication; both have been emphasised as pivotal to overcoming barriers to
478 medicines use in the current review.

479 A systematic review of interventions to improve adherence in people with cognitive
480 impairment included only 3 studies (Campbell et al., 2012). The interventions ranged from
481 reminders and compliance aid medication boxes at the care recipients' home, a
482 telephone/televideo medication reminder, and refill reminder postcards and medication
483 schedules. Findings did not show significant benefits, but a recurring message was the
484 importance of continuous interaction and communication with PLWD.

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

490 **5. Implications for research**

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

496 Future studies should also examine the implications of choice of different routes of
497 administration and dosage forms and should endeavour to include the views of both PLWD
498 and their caregivers. Recommendations can then be given to achieve patient-centric care
499 regarding effective medicines use for PLWD. Healthcare professionals also need to
500 understand the importance of asking about how medicines are being taken or given to ensure
501 they are being adhered to and administered safely and effectively, leading to acceptability
502 both for PLWD and their caregiver. There is also a need for better education and support

503 provision, and future research should focus on interventions with a wider scope that do not
504 focus on adherence but on the medication use process to improve medicines use for this
505 population. In order for interventions to be successful, the needs of PLWD and their
506 caregivers need to be taken into account when developing them (Brodaty and Donkin, 2009).

507 **6. Limitations**

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

515 **7. Conclusion**

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

525

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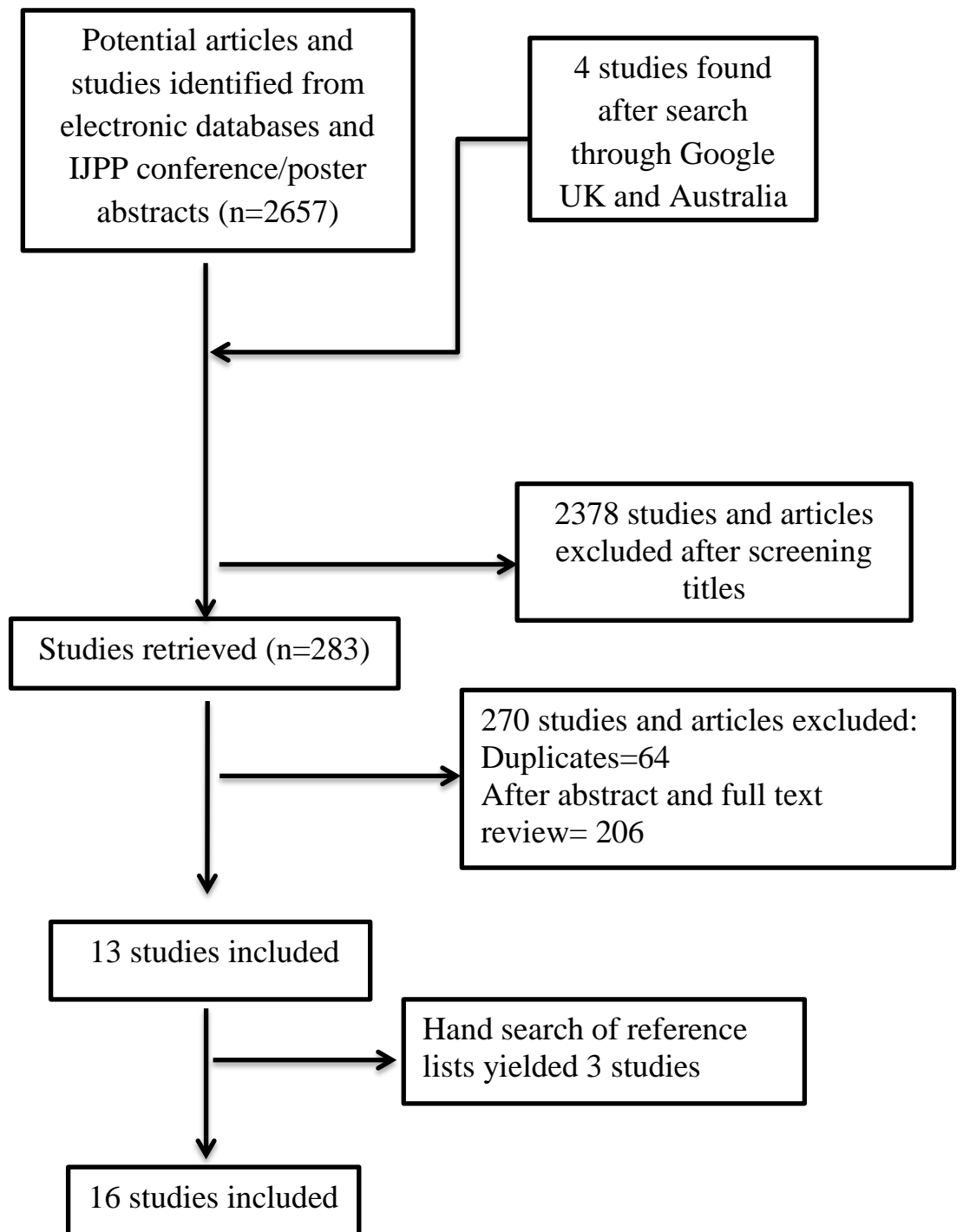


Figure 1: Literature review process flowchart

Table 1: Eligibility criteria for included studies

Eligibility criteria
Qualitative, quantitative, or mixed-methods
Perspective of PLWD, caregiver, or both
Caregivers included family caregivers and carers or nurses from care homes
States that patients have form of dementia
In the English language

Table 2: Characteristics of qualitative studies

Author	Country	Type (number) of participants	Method of data collection	Methodology	Aim of the study
Travis et al. (2000)	USA	Family caregivers (23)	Interviews	Content analysis	To identify medication administration hassles from the perspectives of family caregivers of older patients
Lau et al. (2009)	USA	Hospice providers (22), family caregivers (23)	Interviews	Content analysis, thematic coding	To identify family caregiver medication management skills for home hospice patients
Hutchings et al. (2010)	UK	Family caregivers (11), PLWD (12)	Interviews, focus groups	Thematic analysis	To learn PLWD and caregivers' experiences of using cholinesterase inhibitors
Taylor and Weiss (2010)	UK	7 case groups; each group consisting of the PLWD, their main caregiver and the PLWD's prescriber	Interviews	Interpretative phenomenological analysis	To explore the views on dementia medicines from PLWD in the early stage of the condition, their main caregiver and their prescriber over time.
Kaasalainen et al. (2011)	Canada	HCPs (26), family caregivers (20), PLWD (11)	Interviews	Grounded theory	To explore medication management experiences from the perspectives of PLWD in the community, their informal caregivers, and HCPs who are involved in their care
Carder (2012)	USA	Paid carers at care homes (16)	Interviews, observation	Grounded theory	To explore care home staff members' decision-making process to administer PRN medications to residents with dementia

Author	Country	Type (number) of participants	Method of data collection	Methodology	Aim of the study
Jansen et al. (2012)	UK	Bereaved caregivers (6), HCPs (6)	Interviews	Narrative analysis	To explore caregivers' and HCPs' experiences regarding decisions about medication options for PLWD at end-of-life care
While et al. (2012)	Australia	Family caregivers (9), PLWD (8)	Interviews	Grounded theory	To explore the medication management experiences of PLWD in the community and their informal caregivers and comparing their perspectives with those of people without dementia
De Witt Jansen et al. (2013)	UK	Nurse home managers (3), nursing staff (8)	Interviews	Thematic analysis	To explore nursing home managers' and staff members' experiences of administering medicines to residents with dementia
Mirk et al. (2013)	USA	Family caregivers (19), elderly people (27)	Medication management visit	Not reported	To employ the IMPROVE model to determine problems encountered by elderly patients and their informal caregivers with medication management
Poland et al. (2014)	UK	Family caregivers (9)	Focus group	Thematic and narrative analysis	To gain caregivers perspectives on medication issues and how they are dealt with
Smith et al. (2015)	UK	Family caregivers (14), PLWD (5)	Interviews	Thematic analysis	To identify the types of medicines-related assistance provided by family caregivers of PLWD and the problems surrounding it
Gillespie et al. (2015)	Australia	Family caregivers (29)	Interviews, Focus groups	Thematic analysis	To examine the medication management experiences of ethnic minority family caregivers of PLWD

Table 3: Characteristics of studies that employed quantitative or mixed methods

Author	Country	Type (number) of participants	Method of data collection	Methodology	Aim of the study
Reinhard et al. (2012)	USA	Family caregivers (1,677)	Online survey	NA	To learn the responsibilities of family caregivers relating to medical tasks and the difficulties encountered
Erlen et al. (2013)	USA	Family caregivers (91), PLWD (91)	Interviews, questionnaires, telephone follow-up	Not reported	To examine medication management deficiencies, as well as medicine taking issues, encountered by PLWD and their caregivers in the community
Maidment et al. (2013)	UK	Alzheimer's Society Research Network Volunteers (20), family caregivers	Focus group, survey	Not reported	To explore the role of informal caregivers relating to safe medication management and the issues involved

Table 4: Themes derived from the studies

Theme	Sub-themes
Organisation and scheduling Logistics ^{1,2,4,8,11,15,16}	<ul style="list-style-type: none"> • 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 ^{1-6, 8-16}	<ul style="list-style-type: none"> • 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 ^{1, 3-16}	<ul style="list-style-type: none"> • 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 ^{5, 8-10, 14-16}	<ul style="list-style-type: none"> • 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 ^{8, 5, 14-16}	<ul style="list-style-type: none"> • 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 ^{2, 5, 7, 8, 14-16}	<ul style="list-style-type: none"> • 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
<p>1. (Travis et al., 2000), 2. (Lau et al., 2009), 3. (Hutchings et al., 2010), 4. (Taylor and Weiss, 2010), 5. (Kaasalainen et al., 2011), 6. (Carder, 2012), 7. (Jansen et al., 2012), 8. (While et al., 2012), 9. (Reinhard et al., 2012), 10. (De Witt Jansen et al., 2013), 11. (Mirk et al., 2013), 12. (Erlen et al., 2013), 13. (Maidment et al., 2013), 14. (Poland et al., 2014), 15. (Gillespie et al., 2015), 16. (Smith et al., 2015)</p>	

