



Challenges to optimal medicines use in people living with dementia and their caregivers: A literature review



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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.

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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; Sørensen 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

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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: ‘Dementia’ OR ‘Alzheimer’s’ OR ‘Mild cognitive impairment’ AND ‘Caregiver*’ OR ‘Carer*’ OR ‘Care home*’ OR ‘Carer centre*’ AND ‘Medication*’ OR ‘Prescription*’ OR ‘Pharmaceutical*’ OR ‘Drug*’ OR ‘Formulation*’ OR ‘Dosage form*’ AND ‘Barrier*’ OR ‘Challenge*’ AND ‘Medication administration’ OR ‘Medication management’ OR ‘Medication use’.

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. Fig. 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

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

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