SYSTEMATIC REVIEW

Interventions for self-management of medicines for community-dwelling people with dementia and mild cognitive impairment and their family carers: a systematic review

Catherine Powell[1,2], Justine Tomlinson[1,2,3], Catherine Quinn[4,2], Beth Fylan[1,5,2]

[1]School of Pharmacy and Medical Sciences, University of Bradford, Bradford, UK
[2]Wolfson Centre for Applied Health Research, Bradford, UK
[3]Medicines Management & Pharmacy Services, Leeds Teaching Hospitals NHS Trust, Leeds, UK
[4]Centre for Applied Dementia Studies, University of Bradford, Bradford, UK
[5]NIHR Yorkshire and Humber Patient Safety Translational Research Centre, Bradford Institute for Health Research, Bradford, UK

Address correspondence to: Catherine Powell, School of Pharmacy and Medical Sciences, University of Bradford, Room M24, Richmond Building, Richmond Rd, Bradford BD7 1DP, UK. Tel: +44 (0)1274 236338. Email: c.powell2@bradford.ac.uk

Abstract

Background: people with dementia or mild cognitive impairment (MCI) and their family carers face challenges in managing medicines. How medicine self-management could be supported for this population is unclear. This review identifies interventions to improve medicine self-management for people with dementia and MCI and their family carers, and the core components of medicine self-management that they address.

Methods: a database search was conducted for studies with all research designs and ongoing citation search from inception to December 2021. The selection criteria included community-dwelling people with dementia and MCI and their family carers, and interventions with a minimum of one medicine self-management component. The exclusion criteria were wrong population, not focusing on medicine management, incorrect medicine self-management components, not in English and wrong study design. The results are presented and analysed through narrative synthesis. The review is registered [PROSPERO (CRD42020213302)]. Quality assessment was carried out independently applying the QATSDD quality assessment tool.

Results: 13 interventions were identified. Interventions primarily addressed adherence. A limited number focused on a wider range of medicine self-management components. Complex psychosocial interventions with frequent visits considered the person's knowledge and understanding, supply management, monitoring effects and side effects and communicating with healthcare professionals, and addressed more resilience capabilities. However, these interventions were delivered to family carers alone. None of the interventions described patient and public involvement.

Conclusion: interventions, and measures to assess self-management, need to be developed which can address all components of medicine self-management to better meet the needs of people with dementia and MCI and their family carers.

Keywords: dementia, mild cognitive impairment, medicine, community dwelling, systematic review, older people

Key Points

- People with dementia and mild cognitive impairment and their family carers need support in the self-management of medicines.
- Only a few interventions target medicine self-management beyond adherence.
- Interventions lack appreciation for the complexity of medicine self-management and risks to patients inherent in the system.

Introduction

Supporting people with dementia and mild cognitive impairment (MCI) is a global health priority. Worldwide, there are estimated to be over 50 million people with dementia [1] and within the UK approximately 850,000 [2]. People with dementia are more likely to have comorbidities, [3] which could lead to polypharmacy [4]. The cognitive difficulties associated with dementia and MCI can increase the complexity of managing multiple medicines.

The challenges of medicine management are manifold. An all-party parliamentary report highlighted issues such as family carers lacking information to administer medication, communication gaps between professionals, and a lack of an overall holistic approach [5]. Appropriate support tackling medicines management issues are therefore needed.

Medicine management interventions could improve partnerships between healthcare professionals, the person and family; reduce errors and iatrogenic disease; improve the quality of life and enhance dementia care overall [6]. Community-based interventions are being developed that target some of these core medicine management challenges. For example, a qualitative intervention development study drew on community pharmacy and general practitioner (GP) perspectives, creating an intervention for community pharmacists to conduct a medication review with adherence monitoring [7].

Self-management interventions could enhance the safe and optimal use of medicines by people with dementia and their carers. Increasingly, active participation of people in their own healthcare is emphasised with, for example, the National Health Service (NHS) long-term plan advocating 'supported self-management' [8]. Self-management typically involves drawing on knowledge and skills; goal setting, monitoring behaviour and evaluating, and is often defined as 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition', [9] and may incorporate sources of support from family and the community [10]. Benefits of a self-management approach include enhancement in the quality of life, self-efficacy, knowledge and skills to manage illness and stress reduction [11]. Applied to medicines, self-management has been defined as 'the extent to which a patient takes medication as prescribed, including not only the correct dose, frequency, and spacing but also its continued, safe use over time' [12]. Some patients can self-manage their medicine routines and enhance safety in the system through under-recognised actions [13, 14].

Self-management interventions have lacked theoretical underpinnings. Some cite social cognitive and self-efficacy theories by which individuals hold a belief that they can complete an action [15, 16]. A resilient healthcare (Safety II) approach emphasises how the flexibility and adaptability of healthcare systems can result in safe outcomes [17]. Patients and their families have been overlooked in this process, yet they play major roles in safe medicine management [14]. It is unclear which interventions could support patient involvement [18].

Self-management for people with dementia has been a relatively unexplored concept. Limited self-management interventions have been developed for people with early-stage dementia [19, 20]. In a systematic review of self-management interventions for people with dementia and MCI, Quinn *et al*. identified self-management components commonly incorporated into interventions. These included 'information', 'self-monitoring' and 'skills training' [20]. There is limited understanding of which intervention components could address medicine self-management for people with dementia and MCI and family carers.

Therefore, in this study we sought to understand:

Which interventions improve medicine self-management for community-dwelling people living with dementia and MCI, and family carers?

Which components of medicine self-management are targeted by interventions aimed at community-dwelling people living with dementia and MCI and their family carers?

Methods

To ensure rigour in the process, the Preferred Reporting Items for Systematic Reviews and Meta-analyses checklist is presented (Supplementary data, Appendix 1). The review is registered [PROSPERO (CRD42020213302)].

Search strategy and selection criteria

A search was conducted from May 2020 to December 2021. Searches included articles from database inception up to 2020. The following databases were initially searched in May 2020: Medline (EBSCO), (Cumulative Index to Nursing and Allied Health Literature: EBSCO), EMBASE, Cochrane Database of Systematic Reviews and clinicaltrials.gov. Systematic reviews were hand-searched for relevant articles. A forward and backward citation search was conducted on included articles. Google Scholar was searched limited to the first 50 results. The search was updated in Medline, and PsycInfo was searched up to December 2021. Supplementary data, Appendix 2 outlines our search.

A process of search term development involved drawing on clinical, research and patient experience. We consulted a patient public involvement group to develop terms and expert subject librarians for search terms as well as the full search strategy. The Medical Subject Headings terms and key words included were based on four key concepts: 'dementia/mild cognitive impairment', 'self-management', 'medicines' and 'family carers'.

Studies needed to include an intervention for people with dementia or MCI, or their family carers. Participants had to live within the community, excluding care homes. All age groups were included as also a range of study designs. Only articles written in English were included. All studies had to include at least one medicine self-management component. The definition of medicine self-management from a person's perspective is limited; we therefore sought to enhance the definition. We identified defining features of

medicine self-management from the literature, [12–14] finding potential components such as recognising side effects, or reading the medicine labels [21, 22]. To further consolidate our definition from the patients' perspective, we consulted a patient public involvement group. Medicine self-management components identified and sought included checking for errors, seeking support, adherence, knowledge, supply management and monitoring effects. The exclusion criteria were wrong population, not focusing on medicine management, incorrect medicine self-management components and wrong study design (non-intervention studies, theses and systematic reviews).

Review process

Title, abstract and full-text screening were conducted by all four reviewers. Disagreements were resolved through discussion. Full details of the screening process are provided in Supplementary data, Appendix 2. A data extraction form was created, and the process was carried out by author 1, which was checked for accuracy by author 2 and author 4. Author 2 checked all included articles.

Author 4 checked a subset of articles that have evidence of interventions aimed at resilience abilities in medicine self-management: ability to respond, such as being able to respond to changes; ability to monitor, awareness of what to look out for; ability to learn, awareness of what has happened and being able to learn from this; and ability to anticipate, such as knowing what to expect [17, 23, 24].

Quality assessment was carried out independently by author 1 and author 2 applying the Sirriyeh et al. 16-item quality assessment tool (QATSDD) designed for health service research across different disciplines in qualitative and quantitative research. Using this method, each paper was awarded a quality score with a higher score indicated a better quality paper [25].

Data synthesis

Due to significant heterogeneity in the study designs, a narrative approach was applied to describe the identified medicine self-management interventions for people with dementia and their family carers. Data synthesis was undertaken by author 1 and author 2 and reviewed by author 4 and author 3 for accuracy and completeness.

Results

In all 2,947 articles were identified in the search, of which 2,934 were excluded. Thirteen studies were included in the review. The majority of studies (seven) were conducted in the United States, [26–31] two in Japan, [32, 33] one in Australia, [34] one in Spain, [35] one in Mexico [36] and one in Korea [37].

Following the quality assessment, a decision was made to include all studies regardless of score as the quality of studies was relatively low. Only two studies received a rating score

above 70%, at 71.42% [35] and 72.91% [36]. The quality assessment revealed no patient public involvement in any of the studies.

Supplementary data, Appendix 3 provides an overview of the studies. Study samples were diverse in types of dementia and MCI. Studies were tested through a variety of research designs, including one quantitative and qualitative evaluation within a feasibility study [34], six randomised controlled trials [26, 28, 29, 36–38], one controlled trial [30], three quasi-experimental pre-test and post-test design [27, 32, 33], one retrospective study [31] and one repeated measures design [35]. All studies reported quantitative outcomes, and six studies reported qualitative outcomes [27, 30, 32–34, 36, 38].

Erlen et al. [26], Linger et al. [38] and Kim et al. [37] included interventions focused on family carers alone. Interventions varied from exclusively targeting the person with dementia or MCI, [36] or family carers [38]. Some interventions sought to target both people with dementia and family carers. Only one home monitoring intervention was targeted towards people living alone [30]. Some interventions required a family carer to assist with filling medication devices and monitoring the person's condition [32], monitoring the use of a medication dispenser [33], and one study found the medication ambient display (MAD) system supported families in reminding their relatives to take medicines [36]. Interventions were delivered by a range of healthcare professionals, GPs, [34] pharmacists, [31, 34] occupational therapists, [29] nurses [26, 30, 37, 38] and social workers [26, 38].

Most interventions involved reminder devices to aid adherence; however, some were complex involving, for example, healthcare and social work professionals working closely with individuals on personalised workbooks and having frequent home visits. All studies sought to enhance patients' adherence to medicines. Complex interventions providing personalised support targeted a broader range of medicine self-management components and could support more aspects of patients' resilience, potentially enhancing safer use of medicines for patients.

Six used medication compliance devices [27, 28, 30, 32, 33, 36], one of which was combined with a personalised booklet [28] and another with a compliance aid also involved home visits by occupational therapists [29]. One intervention was a computerised memory development intervention, the differential outcomes procedure [35]. Two interventions included pharmacist-led medicine reviews [31, 34]. Two studies involved home and phone visits and a workbook [26, 38].

Interventions were educational or provided reminders to patients. Ten of the thirteen interventions sought to educate patients [26–29, 31, 34–38]. Type of education ranged from advice related to medication use [37], storage and management, simplification of the regimen [34], personalised provision of a written action plan [29], problem-solving workbook [26] and tailoring information and advice to be personalised and in own language [28]. Of the compliance

device interventions, two tested an automatic alarmed medication dispenser [32, 33], one intervention involved an alarmed pill box and all participants were exposed to a pictorial medication sheet with pictures and brief descriptions of medicines and dose [27]. A pill organiser was utilised for some patients as part of the overall occupational therapy behavioural intervention [29].

Compliance aid interventions were often delivered remotely, with telecare prompting evident in three interventions [28, 30, 36] applying automated reminders in one [28], video and telephone monitoring [30], and MAD [36]. Components of interventions were also delivered by home visits [29, 34, 38], with for example one intervention carrying out a medication review with the patient in their own home [34].

Most interventions had weak or no theoretical underpinnings. Dong *et al*. [31] applied the Gelberg–Andersen Behavioural Model for Vulnerable Populations as a conceptual framework [39]. Two interventions were underpinned by social cognitive and self-efficacy theories [27, 38]. The interventions included specific self-management components that promoted: adherence, patient knowledge and understanding, supply management and monitoring effects and side effects. The promotion of adherence was a core component of all interventions, and it predominantly focused on enhancing a patient's ability to follow a specific medicine regimen [26–38]. Enhancing patient knowledge and understanding of medicines to support self-management was found in ten interventions [26–29, 31, 34–38]. Supply management was promoted in only two interventions [26, 38]. One intervention involved checking medicine supplies and resolving medicine errors and seeking support from healthcare professionals [38]. Monitoring effects and side effects of medicines was described in two studies [34, 37].

We identified resilience capabilities. Ten interventions focused on improving the ability to learn [26, 27, 29, 31–35, 37, 38]. System resilience capabilities for most interventions focused on improving patient learning on how to adhere [27, 29, 32–35]; however, the ability to learn also included how to communicate with physicians [26], learning about medicines [27] and about roles in medicine management [38]. Two interventions sought to enhance the ability to anticipate: one for adherence problems [29] and another included medication errors [38]. Four focused on the ability to monitor [28, 32, 36, 37] and three on the ability to respond [26, 29, 38].

Effect of interventions

The seven interventions involving compliance aids were largely successful at enhancing adherence for people with dementia and MCI. Two randomised controlled trials of compliance aids showed improvements in adherence. Two used a personalised booklet on their treatment. Measures were conducted weekly through pill counting from week 6 pre-intervention period to week 16 post-intervention period [36] and baseline, and followed each month for 12 months, and at three-month intervals for a second year [28]. Medication compliance at the end of the study remained stable at 81% for a video-monitored group compared to 66% in control, and qualitative analysis also indicated that the intervention improved accuracy of the number of medicines [30]. One repeated measures design [35] enhanced adherence compared to the control group (95.97% compared to 88.18%). Three quasi-experimental pre-test post-test design [27, 32, 33] studies were conducted. One enhanced adherence and enhanced error avoidance and facilitated discussion with healthcare professionals [27]. Thus, compliance aid interventions were primarily effective at enhancing patients' adherence.

An intervention using home visits and a workbook for family carers, focused on developing a wider range of medicine management components, found both treatment and control groups had reduced medication management deficiencies such as forgetting to take medicine, potentially due to the focus on medicine management during data collection. However, 92% reported improvements in managing the treatment plan, and 88% family carers reported that the intervention topics were relevant and useful [38]. Erlen *et al*. [26] using home visits and a workbook also found decreases in sustained medicine deficiencies, family carer self-efficacy and mental health-related quality of life in both control and intervention groups. Physical health-related quality of life increased in the intervention group, compared to decrease in usual care. Although, problem-solving, daily hassles and healthcare utilisation had no significant changes. Daily hassles were measured by The Hassles subscale of the 53-item Combined Hassles and Uplifts Scale to identify daily situations with managing medicines leading to distress [40]. More research is needed with diverse samples, particularly with less experience of medicine management [26]. A nurse-led education programme focused on donepezil use and Alzheimer's found donepezil adherence similar in both intervention and control. Low discontinuation rates meant there was no significant difference in adherence [37]. Interventions delivered by occupational therapists baseline and months 6 and 12 found improved glycaemic control in older African-Americans with MCI and poor glycaemic control. The interventions were an occupational behavioural therapy intervention and diabetes self-management education delivered at home. This involved behavioural activation techniques to reinforce action plans [29]. One pharmacist-led medicine review showed some promising results for medication adherence. Across three conditions in one year, non-adherence decreased in the intervention group (diabetes 13.1–9.8%, hypertension 16.39–12.50% and hyperlipidemia 18.69–11.72%). Another pharmacist review focused on medication appropriateness, medication adherence and medication management intervention, with qualitative measures on pharmacist involvement in a memory clinic, described patients increased understanding and confidence with medication. The intervention simplified the regimen in collaboration with the GP to optimise medication.

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Additional themes described the intervention as helpful for medication use and storage [34].

Discussion

This systematic review aimed to identify interventions to improve medication self-management and which medicine management components are targeted by these interventions. As a secondary outcome, we identified whether these interventions supported resilience strategies, enabling patients to be fully involved in their medicine self-management. Overall, our findings indicate that there are interventions to improve medicine self-management; however, they all primarily focus on enhancing adherence, more often reminding patients to take their medicines.

While interventions showed promise in enhancing adherence, only two interventions focused on more of a broader understanding of medicine self-management, incorporating wider elements of resilience characteristics and medicine management components [26, 38] adopting a psychosocial approach. One intervention did have a broader range of medicine management components but addressed only one area of resilience [34]. Thirteen interventions utilised different approaches including pharmacist-led medicine reviews [31, 34], a workbook [26, 37], medication compliance devices [27, 28, 30, 32, 33, 36], home visits by occupational therapists [29], home visits, telephone follow-up by a nurse or social worker and a workbook [38], and a computerised memory development intervention [35]. All of these interventions supported adherence, while ten supported knowledge enhancement [26–29, 31, 34–38]. Yet other key medicine self-management components, such as supply management, monitoring of effects and side effects, and communicating with healthcare professionals were infrequent. Where these components were evident, these tended to be complex psychosocial interventions with frequent home/telephone visits or workbooks with content tailored to the individual, designed with a broader conception of medicine self-management and self-efficacy [26, 38]. These interventions addressed a wider range of resilience capabilities; ability to learn, ability to anticipate and solve problems [26], and the ability to respond and anticipate [38].

While interventions using home visits/telephone follow-up and workbooks targeted a wider range of resilience capabilities and medicine management components, resource implications such as staff time and training to deliver such interventions need consideration. For example, Rovner *et al.*'s [29] occupational therapists delivered 720 minutes of in-home sessions. These interventions are resource intensive. Their wider scale implementation and impact on patient outcomes requires further research.

A theory-driven approach is more likely to improve the effectiveness, sustainability and scalability of an intervention [41]. Both Erlen *et al.*'s and Lingler *et al.*'s [26, 38] interventions were tailored problem-solving interventions informed by social cognitive and self-efficacy theories [42,

43]. A medicine self-management intervention underpinned by self-efficacy has greater potential to meet better the psychosocial needs of people with dementia and MCI and their family carers. Self-efficacy is a core tenet of self-management interventions [20, 44]. Yet only a few medicine self-management interventions for people with dementia and MCI as well as their family carers focused on self-efficacy. Future medicine self-management interventions should therefore seek to identify and make use of appropriate theory.

Research has indicated the importance of involving people with dementia and family carers across stages of the design process, and taking a co-design approach to interventions [44]. However, none of the studies in our review described a co-design process or patient and public involvement. Without the perspective of patients, such interventions will be limited in effectively addressing real needs and patient priorities, which go beyond adherence. Moreover, the interventions for people with dementia and MCI were primarily simple reminder interventions involving medicine compliance devices. In contrast, the more complex interventions addressing the broader range of medicine self-management needs were targeted towards family carers. However, we know from self-management research that people with dementia themselves can benefit [19, 44, 45]. It is therefore crucial that interventions are designed according to patient and family carer needs, encompassing medicine self-management experiences, that is, as a whole rather than adherence alone.

Further research needs to develop and test interventions underpinned by patients' and family carers' broader experience of processes involved and resilience capabilities in medicine self-management. Interventions should focus on more than adherence because there may be safety implications of an adherence focus alone. Taking a person-centred approach, drawing on patients' beliefs about their own care could enhance self-management as it includes a broader understanding of medicine self-management. Medicine management needs to incorporate patients' and family carers' full role in supply management, checking of their medicines and error resolution, seeking support from healthcare professionals, monitoring effects and side effects, and knowledge and understanding of medicines to support management. Incorporating a resilience lens within intervention design enables a wider system view of the patient role in safe medicine management, including how patients and carers contribute to whole system safety through their self-management routines. For example, the system is safer overall if patients can detect errors. Interventions need to be developed which are not purely for family carers but support the involvement of the person with dementia. Patient-reported outcome measures for self-management also need to be developed. An intervention needs to be developed and tested appropriate to the existing health systems, which may be country specific. It is unclear how generalisable the interventions in this review are as they were developed in a limited range of countries. However, there are

interventions to improve self-management for people with dementia without specific medicines focus in some countries such as the UK [19, 44, 46, 47].

Strengths and limitations

Key strengths included the thorough review process highlighting a limited area of research, and the inclusion of different study designs. Limitations to the review process included significant heterogeneity in the study designs and involving studies with a minimum of one self-management component. Some descriptions of interventions had limited detail, and therefore it may not have been possible to identify some aspects of medicine self-management or resilience components. The samples in some studies were mixed. Only English language papers were included. Medicine self-management measures limited our ability to draw firm conclusions which could hinder developing effective interventions. The quality of studies was relatively low based on criteria such as sample size justification, patient involvement in design, and theoretical underpinnings [25].

Conclusion

Few interventions address core challenges people with dementia and family carers face in self-managing medicines. Patient safety, outcomes and quality of life may be enhanced through co-developing interventions and measures of medicine self-management with patients and family carers, drawing on their capabilities, addressing adherence in addition to other medicine management components.

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