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Recommended Citation

Gillespie, Robyn; Mullan, Judy; and Harrison, Lindsey, "Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature" (2014). *Faculty of Science, Medicine and Health - Papers: part A*. 1621.

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Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature

Abstract

Aims and objectives To explore published literature that describes what is known about the role of informal caregivers as they manage medications for older adults and/or people living with dementia residing in the community. **Background** The number of informal caregivers of older adults, including people living with dementia, is growing worldwide. Good medication management by informal caregivers contributes to improved health outcomes and reduced institutionalisations for the care recipient; however, little is known about this domain of care. **Design** Narrative review. **Methods** A literature search was conducted to identify relevant research articles written in English between January 2000-April 2013, sourced from online database searches using multiple keywords, reviewing reference lists and citations of key articles and Internet searches. Articles were included if they described informal caregiver medication management for older adults and/or people living with dementia. **Results** Ten articles were found that described this role from the perspective of the informal caregiver. The evidence suggests that this role is complex and is often made more difficult because of increasing medication regimen complexities, aspects of the relationship between the caregiver and the care recipient, healthcare system practices and a lack of information and/or training available to the informal caregiver, especially when caring for people living with dementia. **Conclusion** Responsibility for managing medications for older adults and/or people living with dementia in the community often falls to informal caregivers. More information resources are required for this role, which requires specific medication management skills and knowledge and is further complicated by the cognitive decline of the care recipient.

Disciplines

Medicine and Health Sciences | Social and Behavioral Sciences

Publication Details

Gillespie, R., Mullan, J. & Harrison, L. (2014). Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature. *Journal of Clinical Nursing*, 23 (23-24), 3296-3308.

Review

**Managing medications: the role of informal caregivers of older adults and people living
with dementia. A review of the literature.**

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Text word count: 4081

Acknowledgements

This work was supported by the Multicultural Health Service Health Reform Transitional Organisation Southern Cultural Diversity Health Enhancement Grant South Eastern Sydney and Illawarra Shoalhaven Local Health Districts

Conflict of interest

The authors declare that they have no conflicts of interests.

Aims and objectives. To explore published literature which describes what is known about the role of informal caregivers as they manage medications for older adults and/or people living with dementia (PLWD) residing in the community.

Background. The number of informal caregivers of older adults, including PLWD, is growing worldwide. Good medication management by informal caregivers contributes to improved health outcomes and reduced institutionalisations for the care recipient, however little is known about this domain of care.

Design. Narrative review

Methods. A literature search was conducted to identify relevant research articles written in English between January 2000 and April 2013, sourced from online database searches using multiple keywords, reviewing reference lists and citations of key articles and internet

searches. Articles were included if they described informal caregiver medication management for older adults and/or PLWD.

Results. Ten articles were found which described this role from the perspective of the informal caregiver. The evidence suggests that this role is complex and is often made more difficult because of increasing medication regimen complexities, aspects of the relationship between the caregiver and the care recipient, health system practices and a lack of information, and/or training available to the informal caregiver, especially when caring for PLWD.

Conclusion. Responsibility for managing medications for older adults and/or PLWD in the community often falls to informal caregivers. More information resources are required for this role, which requires specific medication management skills and knowledge and is further complicated by the cognitive decline of the care recipient.

Relevance to clinical practice. Informal caregivers are often expected to manage medications in a safe and effective manner for their older care recipient, who may also have cognitive impairment. Nurses, who may be in frequent contact with community living older adults/PLWD, can be an important source of information, training and support for informal caregivers.

Summary Box: What does this paper contribute to the wider global clinical community?

- This review of the literature raises awareness of the complexity of the medication management role of informal caregivers and the significant difficulties they face in safely and effectively managing medications for older adults and/or people living with dementia in the community setting. Informal caregivers of people living with

dementia often face additional difficulties in carrying out their medication management role.

- Significant training is given to health professions carrying out the medication management role; however this review reveals that informal caregivers receive little education, resources and /or training in preparation for this role.
- This review encourages nurses who visit older adults and/or people living with dementia in the community setting to provide information, training and support to informal caregivers in their medication management role.

Key words:

Carer, Dementia Care, Elder Care, Ethnicity, Literature Review, Medication Management

Introduction

The number of older people likely to require assistance from informal caregivers in the community setting is growing as a result of population and epidemiological changes (Bookman & Harrington 2007). In developed countries, including North America, Europe, Japan, Australia and New Zealand, the number of people aged over 65 years has been rapidly growing, as a percentage of the total population, from 7.9% in 1950, to 20.6% in 2010 (United Nations 2011). Accompanying this demographic transition is an epidemiologic transition with increasing morbidity and mortality related to chronic and degenerative diseases (World Health Organisation 2008). Dementia is one such disease, and is the fourth highest cause of years lost to disability in developed countries (WHO 2008). In 2010, the prevalence of people living with dementia, aged over 60 years in developed countries was estimated to be approximately 6.5%. Prevalence globally is predicted to almost double from 35.6 million people in 2010 to 66 million by 2030 (Alzheimer's Disease International 2009).

Medication management has been identified as one of many domains of care given by informal caregivers in the community setting (Fortinsky 2001; Brodaty & Green 2002). For example, a recent USA based online survey found that 607 (36%) out of 1,677 informal caregivers, reported that they managed medications for the person in their care (Reinhard *et al.* 2012). This is a very important role, since good medication management by informal caregivers contributes to improved health outcomes and reduced institutionalisations for the care recipient (Arlt *et al.* 2008).

Furthermore, this informal caregiver role becomes more crucial when the care recipient has been diagnosed with dementia and their cognitive function declines, resulting in additional barriers to the management of their own medications in a compliant and safe manner (Cotrell *et al.* 2006, Westerbotn *et al.* 2008, Erlen *et al.* 2013). Based on data from a US research project 'Resources for Enhancing Alzheimer's Caregiver Health' (REACH),

approximately 54% of informal caregivers had daily medication management responsibilities for PLWD, which increased to over 90% in the later stages of the care recipients' dementia (Thorpe *et al.* 2012).

Given that informal caregivers, especially those caring for PLWD, commonly manage medications, it is logical to seek to understand their needs in support of this role. An awareness of these needs will ensure that strategies and interventions can be developed to help support them to manage their care recipients' medications in a safe and effective manner. Nurses, who often visit older adults and/or PLWD residing in a community setting, are well positioned and have unique competencies to provide support, training and information for this growing group of informal caregivers, particularly in relation to aspects of their medication management roles (Whittingham & Pearce 2011).

The aim of this review then is to explore published literature which describes what is known about the medication management role carried out by informal caregivers, as they care for older adults living in the community. As a subset of this group, additional aspects of the medication management role carried out by informal caregivers of community dwelling people living with dementia (PLWD) are reviewed.

Research Questions

This review asks: what is already known about the medication management role provided by informal caregivers as they care for older adults in the community setting? What additional information is known regarding the role of medication management by informal caregivers of community living PLWD? The results of this review will then be discussed and applied to inform health professionals, and especially nurses' understanding about how to better support this aspect of informal caregiving.

Methods

A literature search was conducted to identify original research articles relevant to the research aim. Literature searches were carried out in the following databases: Scopus, CINAHL, MedLine and ProQuest. Keywords searched included: medication management AND caregivers AND older adults; medicine AND caregivers AND older adults; dementia OR Alzheimer's AND caregiver OR 'Informal care*' OR family caregiv* AND 'medication management' OR 'medication administration'. Key terms searched included: 'medication therapy management' AND 'elder care' AND caregiver. In addition, further searches of reference lists of relevant articles, other articles citing key references and author searches were carried out, as well as an internet search of relevant government and carer support websites.

The search was limited to original research articles, published between January 2000 and April 2013, available in the English language only. Articles were included if they described informal caregiver medication management within community care settings for older adults and PLWD. Articles were excluded from the review if they related to: the medication needs of the informal caregivers rather than the care recipient; discussed self-management of medication by older adults or PLWD only; discussed management of specific medications; or if they were in the context of palliative care, institutional care settings, related to employed caregivers, and/or were additional discussion papers referring to the original research articles already included.

Results

A comprehensive literature search revealed that a limited number of researchers have focused on medication management from the perspective of informal caregivers caring for older adults residing in the community setting, including those caring for PLWD. Ten

relevant original research articles were found. As illustrated in figure 1, a total of 112 articles were retrieved from an initial electronic database search. After review, 104 were initially discarded as they did not meet the inclusion criteria, resulting in 8 relevant articles. One further relevant research article was found following a search of reference lists and citations of key articles and author searches, and a further research article was found following a search of US and Australian informal caregiver support websites.

The 10 original research articles that met the inclusion criteria were reviewed to describe the available knowledge relating to the role of informal caregivers when managing medications for an older adult or PLWD in the community setting. These articles were analysed inductively and key information about this caregiving role was identified, with a view to increase nurses' understanding of this aspect of informal caregiving.

Figure 1 *Flow chart of literature search*

Table 1 summarises each of the 10 reviewed original research articles. The majority of these studies have been carried out in the USA, while others have been conducted in the UK, Canada and Australia. Table 1 highlights the variety of research designs, including both qualitative and quantitative research methods, used for data collection purposes in each of the 10 reviewed original research articles. Those studies that employed only qualitative research methods had relatively small sample sizes of between 17-57 participants, the majority of whom were female informal caregivers, reflective of the gendered nature of caregiving for older people (Travis *et al.* 2000, Francis *et al.* 2006, Duane *et al.* 2011, Kaasalainen *et al.* 2011, While *et al.* 2012). Most studies included ethnic minority caregivers as part of the total sample population (as highlighted in Table 1) although data for these groups were not analysed separately. Only one study focused solely on the medication management roles of ethnic minority caregivers (Duane *et al.* 2011). Furthermore, five of these 10 original research

papers focused, in detail, on the medication management roles of informal caregivers of PLWD (Cotrell *et al.* 2006, Kaasalainen *et al.* 2011, While *et al.* 2012, Thorpe *et al.* 2012, Erlen *et al.* 2013). Table 1 also highlights that study participants were typically selected from a variety of sources ensuring that carers who would not typically identify as informal caregivers were also included in the studies.

Table 1 *Summary of key research articles*

The 10 original research articles reviewed identify various activities carried out by informal caregivers as part of their medication management role. These activities or roles were discussed in two key ways; firstly, descriptions of the types of activities informal caregivers undertake as part of their medication management role, and secondly, descriptions of factors which can impact this role making it more difficult.

Activities informal caregivers undertake as part of their medication management role

In their mixed methods studies, Travis *et al.* (2000) in the US and Smith *et al.* (2003) in the UK, identified similar multiple and often complex informal caregiver medication management roles. These roles included: administering multiple medications (sometimes against the care recipient's wishes) in a safe and effective manner; working out appropriate medication administration schedules; avoiding medication errors and possible drug interactions; looking out for medication side effects, including severe side effects; sometimes having to make judgements regarding when to withhold, increase, decrease or discontinue a medication; maintaining continuous supplies of medications which could involve keeping up to date with multiple prescriptions from multiple prescribers; and trying to make informed decisions about their medication management role by communicating with their care recipients and their health care providers about medications.

In their small qualitative study that included ten informal caregivers from ethnic minority groups, Duane *et al.* (2011) found some additional medication management roles which were assumed by these informal caregivers. These included; accessing health care providers who speak the same language and/or provide culturally appropriate services, acting as interpreters and/or accessing interpreter services, and where possible, accessing relevant translated medication information.

Recently, While *et al's.* (2012) small qualitative study recognised that advocacy, or the act of providing active support, is another important medication management role, especially undertaken by informal caregivers of PLWD. This role may involve advocacy on behalf of health professionals, by administering medications to maintain a therapeutic benefit to the care recipient, or by providing feedback to health professionals on the effectiveness and/or side effects associated with medications administered to the care recipient. On the other hand, advocacy roles may also be carried out on behalf of their care recipient, by checking prescriptions for accuracy, querying changes in medications and/or upholding the medication beliefs and preferences of the PLWD during consultations with their health professionals.

Descriptions of factors that make the medication management role more difficult

Unlike trained health care professionals, informal caregivers face a number of factors that may make their medication management role more difficult and confusing. The following section outlines these factors which have been identified in the current review and include; medication regimen complexity, aspects of the relationship between the caregiver and care recipient, unhelpful health systems and practices, a lack of training and information available to informal caregivers for this role, and further responsibilities arising from the care recipients' increasing cognitive decline, especially among PLWD.

Medication Regimen complexity

Medication regimen complexity often increases as a result of multiple medications being prescribed for multiple co-morbidities during older age and/or in PLWD (Reinhard *et al.* 2012). This increasing medication complexity underlies many of the difficulties described by informal caregivers (Travis *et al.* 2000, Francis *et al.* 2006, Kaasalainen *et al.* 2011, Reinhard *et al.* 2012, Erlen *et al.* 2013). They report managing anywhere between 1-19 prescribed medications, within multiple dosage schedules throughout the day (Francis *et al.* 2006), which in many cases also includes non-prescription medications and supplements purchased over the counter (Reinhard *et al.* 2012). Importantly, Erlen *et al.* (2013) found that informal caregivers who were managing larger numbers of medications were more likely to record inaccuracies in relation to their understanding of how to effectively manage their care recipient's medications, which could contribute to poor therapeutic outcomes. While some of these inaccuracies could be reduced by the use of dosage administration aids, such as organised pill boxes (Kaasalainen *et al.* 2011, Reinhard *et al.* 2012), medications prescribed to be taken 'only as required' cannot be included in these dosage administration aids. Unfortunately, these medications which cannot be packed result in confusion and difficulty particularly for informal caregivers from ethnic minority groups (Duane *et al.* 2011).

Aspects of the relationship between the informal caregiver and care recipient that influence the medication management role

The medication management relationship between an informal caregiver and their care recipient described in the reviewed literature appears to be markedly different to what might be seen in a clinical setting. For example, a subset of the data, using only interviews conducted in English from Smith *et al.*'s (2003) study, revisited by Francis *et al.* (2006),

described the complex and changeable relationships between informal caregivers and care recipients which included:

- sharing of responsibilities for various medication related tasks
- variation in the level of involvement of informal caregivers
- sharing of tasks between more than one informal caregiver
- variation in the level of medication management required by care recipients

Conflict over medication roles was described when the autonomy of the older adult to make their own medication management decisions was undermined by the informal caregiver (Francis *et al.* 2006). Similar conflict over medication issues was also reported in several studies which included informal caregivers of PLWD (Kaasalainen *et al.* 2011; While *et al.* 2012, Erlen *et al.* 2013, Travis *et al.* 2000). Furthermore, Erlen *et al.* (2013) also found that increased care recipient behavioural problems negatively impacted on the informal caregivers' (n=91) ability to manage medications without experiencing medication related errors.

Health system structures and practices

Informal caregivers' medication management roles can be made more difficult by the unhelpful structures and practices in place in different healthcare settings. For example, information regarding medication regimen changes is often not communicated to informal caregivers because they may not have been present during consultations (Francis *et al.* 2006), or because of restrictions placed on providing and sharing confidential information (Smith *et al.* 2003), especially following discharge from hospital. Another frequently raised issue was that the substitution of generic medications was often not properly explained, causing concerns for both informal caregivers and their care recipients (Smith *et al.* 2003, Duane *et al.* 2011, While *et al.* 2012). Similarly, low stock supplies of prescribed medications within

pharmacies and inconsistencies among the number of days of supply for different prescription medicines contributed to the difficulties experienced by informal caregivers (Smith *et al.* 2003, While *et al.* 2012).

Lack of information and support for informal caregivers regarding medication management

Comments on the lack of education and/or resources available to informal caregivers to support them in their medication management role were commonly made in the articles included in this review. Several studies found that informal caregivers had received no training and/or had access to very little information to support them in their medication management roles (Smith *et al.* 2003, Francis *et al.* 2006, Reinhard *et al.* 2012). Once again, the use of ‘only as required’ medications were cited as being especially problematic for informal caregivers who sometimes lacked the knowledge to make clinical decisions concerning the need for and appropriate doses of such medications (Travis *et al.* 2000, Francis *et al.* 2006). A case in point, is the need for informal caregivers to know the risks of administering medications with side effects to their care recipients, such as antihistamines with anticholinergic side effects, (Thorpe *et al.* 2012), which could potentially lead to the increased incidence of sedative side effects and/or falls. This evidence suggests that despite medication management being a complex task, a lack of information and support can contribute to creating barriers for informal caregivers to be able to safely and effectively carry out this role.

Further responsibilities arising from the care recipients’ increasing cognitive decline, especially among PLWD

As mentioned previously, informal caregivers of PLWD are more likely to take on further medication management roles and responsibilities as the cognitive decline of the care recipient progresses. This has been estimated to result in as many as 90% of such informal caregivers undertaking more substantive medication management roles during the later stages

of the care recipients' cognitive disease progression (Thorpe *et al.* 2012). While *et al.* (2012) suggest that the loss of independence of the PLWD in managing their own medications arises because of declining cognitive abilities, changes in medication regimens and changes in their environment and routines following hospitalisation and/or rehabilitation.

Trying to ensure optimal medication compliance therefore becomes an increasingly important medication management role. Using both qualitative and quantitative data methods, Cotrell *et al.* (2006) found that informal caregivers were generally accurate in predicting the PLWD's medication management abilities, but didn't always know how to implement effective strategies to optimise their care recipients' medication compliance. Subsequently, in a qualitative study conducted by Kaasalainen *et al.* (2011), the following strategies were suggested as being useful: establishing medication routines; using dose administration aids; hiding medication in foods; simplifying dosage regimens; and using liquid oral medications (where possible) to improve medication compliance.

Discussion

This review found that little rigorous research has been carried out on the informal caregivers' role in medication management. To date, most of the research literature written about medication management for older adults and/or PLWD living in the community setting has had a narrow focus on studies of medication compliance or adherence (van Eijken *et al.* 2003, George *et al.* 2008, Conn *et al.* 2009). A literature review by Ruppap *et al.* (2008) on medication compliance interventions for older adults, noted that only three of 63 reviewed studies, referred to the role of informal caregivers administering medications, despite the fact that many assist with medication administration. Other studies have focused on the medication management role of formal community health care providers, such as nurses,

pharmacists and doctors (Griffiths *et al.*2004, Kralik *et al.* 2008, Henriques *et al.* 2012), rather than the role of informal family caregivers.

The small amount of research describing aspects of informal caregiver medication management roles over the last decade, whilst being largely descriptive and a-theoretical, has added to the body of knowledge in this previously much neglected area. Based on this research, attention has been drawn to medication management, an important aspect of informal caregiving, the roles and tasks of which remain largely unseen by many, including health professionals and government policy makers, occurring as they do in the private sphere. Reinhard *et al.*(2012) suggest that informal caregivers are expected to perform medication management tasks and these tasks are effectively medical or nursing services. The works of Bookman and Harrington (2007) and Levine *et al.* (2003) call on the real value of informal caregivers to be recognised by health professionals, as part of the healthcare team for the older adult care recipient.

Effective medication management is a vital role of this team, which includes the informal caregiver, in order to ensure the care recipients' safety and to optimise their therapeutic outcomes. Improved informal caregiver access to training, information resources and/or support are particularly important given that, as described in the literature reviewed; informal caregivers face many difficulties in managing medications and currently receive little or no training and/or preparation for this important role. This contrasts with the information and training provided to health care providers carrying out such roles. It could be suggested therefore, that nurses who have regular contact with care recipients' in the community setting could impart some of their knowledge and information to the informal caregivers as part of their role. Alternatively, when and if the opportunity arises, nurses could also be involved in developing, evaluating and distributing more appropriate medication management training/information resources, with additional specific information and support

given to informal caregivers of PLWD. These information and/or training resources should include information about generic medications (Smith *et al.* 2003; Duane *et al.* 2011; While *et al.* 2012), when to give medications prescribed as ‘only as required’ (Travis *et al.* 2000, Francis *et al.* 2006) and where to access information about the side effects of both prescription and non-prescription medications (Thorpe *et al.* 2012), as well as other information which is of major concern to the informal caregiver.

The 10 studies reviewed in this article, illustrate the complex nature of the medication management role taken on by informal caregivers of older adults, including those caring for a PLWD. One additional role, not described in the research articles, but worth noting was mentioned in a discussion paper by Brodaty and Green (2002) and involved the granting or refusing of consent for newly prescribed medications, on behalf of the care recipient who is no longer able to make these decisions. With so many aspects to the medication management role, over time this role could certainly contribute to increased informal caregiver stress (Travis *et al.* 2000, 2007, Smith *et al.* 2003). Once again, the nurse, who has frequent contact with both the care recipient and the informal caregiver in the community setting, is well placed to monitor such stress levels and could provide valuable and timely advice about the availability of additional services and/resources which could help to reduce informal caregiver stress and support them with their medication management role. In cases such as these, nurses could potentially use valid and reliable measures, such as the Family Caregiver Medication Administration Hassles Scale (FCMAHS) (Travis *et al.* 2003, 2007), based on the findings of the study included in this review by Travis *et al.* (2000). The FCMAHS could be used to target interventions for medication management roles that the informal caregivers are finding most difficult. These interventions may be especially useful for informal caregivers of PLWD, given the changeable nature of their medication management role and the conflict they often experience as they manage medications for the PLWD.

This review has identified that medication regimen complexity for older adults is increasing (Reinhard *et al.* 2012) and can make the medication management role of informal caregivers more difficult, in terms of managing medications safely and effectively. Nurses, working alongside informal caregivers in the community setting, are well placed to regularly review the care recipient's current medications by maintaining up to date lists of all medications, including those bought over the counter and advocating on behalf of the care recipient and informal caregiver with prescribing doctors regarding treatment goals and the ongoing place of medications in the care recipient's treatment with a view to reducing regimen complexity where possible.

Countries with projected high percentages of older non-English speaking residents (United Nations Population Division 2009, Department of Health 2009, Department of Health 2012, Australian Government 2012) may face particularly challenging health service provision needs. Support for ethnic minority informal caregivers in their medication management role is a case in point, with evidence in the literature acknowledging that many of these roles and tasks become even more difficult and complex for such groups (Duane *et al.* 2011). In this instance, nurses could assist by directing ethnic minority informal caregivers to available health care providers who speak their language and/or are culturally appropriate, or to appropriate health care support and/or to interpreter services, and when available they could provide them with and/or direct them to appropriate translated medication information.

Limitations of the Review

The limitations of the current review need to be acknowledged. Only a small number of relevant original studies focusing on the medication management roles of the informal caregiver could be found in the literature, with the majority of them conducted in the US, the UK and Australia. The sample sizes of many of the studies reviewed were small and so their

findings may not be able to be generalised to other groups of informal caregivers of older adults and/or PLWD. Furthermore, some issues raised in these studies may not apply in other contexts, where the health care system, support services for older adults and dementia care, and the supply of prescription medications may vary.

Conclusion

Despite the fact that worldwide, there are a growing number of older adults and/or PLWD being cared for in the community setting by informal caregivers, there is limited evidence in the literature regarding their medication management roles. From the research conducted to date, it can be seen that informal caregivers often find this role complex and difficult, and believe that they have limited access to appropriate information resources and/or support to undertake these roles safely and effectively. Health professionals visiting older care recipients in the community setting, and especially nurses, are well equipped to provide information resources, training and/or support to these informal caregivers, thereby enabling them to manage medications for their care recipients safely and effectively.

Relevance to clinical practice

This review highlights the need for nurses in the community setting to be more cognisant and vigilant when considering the various aspects of the medication management role of informal caregivers, caring for older adults and/or PLWD. Nurses are well placed to provide information, training and support for informal caregivers addressing their medication management roles and challenges identified in this review, either individually (Whittingham & Pearce 2011) or during informal caregiver support groups (Hornillos & Crespo 2012). Furthermore, since nurses commonly have access to informal caregivers in many different settings (e.g. community, hospital and rehabilitation) they are also well placed to carry out

further research into this particular caregiver role, which is clearly required given the exploratory nature and limited number of original studies identified in this review.

Contributions

Study design: RG, JM, LH. Data collection and analysis: RG, and manuscript preparation:

RG, JM, LH

Funding

This work was supported by the Multicultural Health Service Health Reform Transitional Organisation Southern Cultural Diversity Health Enhancement Grant South Eastern Sydney and Illawarra Shoalhaven Local Health Districts.

Conflict of interest

The authors declare that they have no conflicts of interests.

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Figure 1 Flow chart of literature search

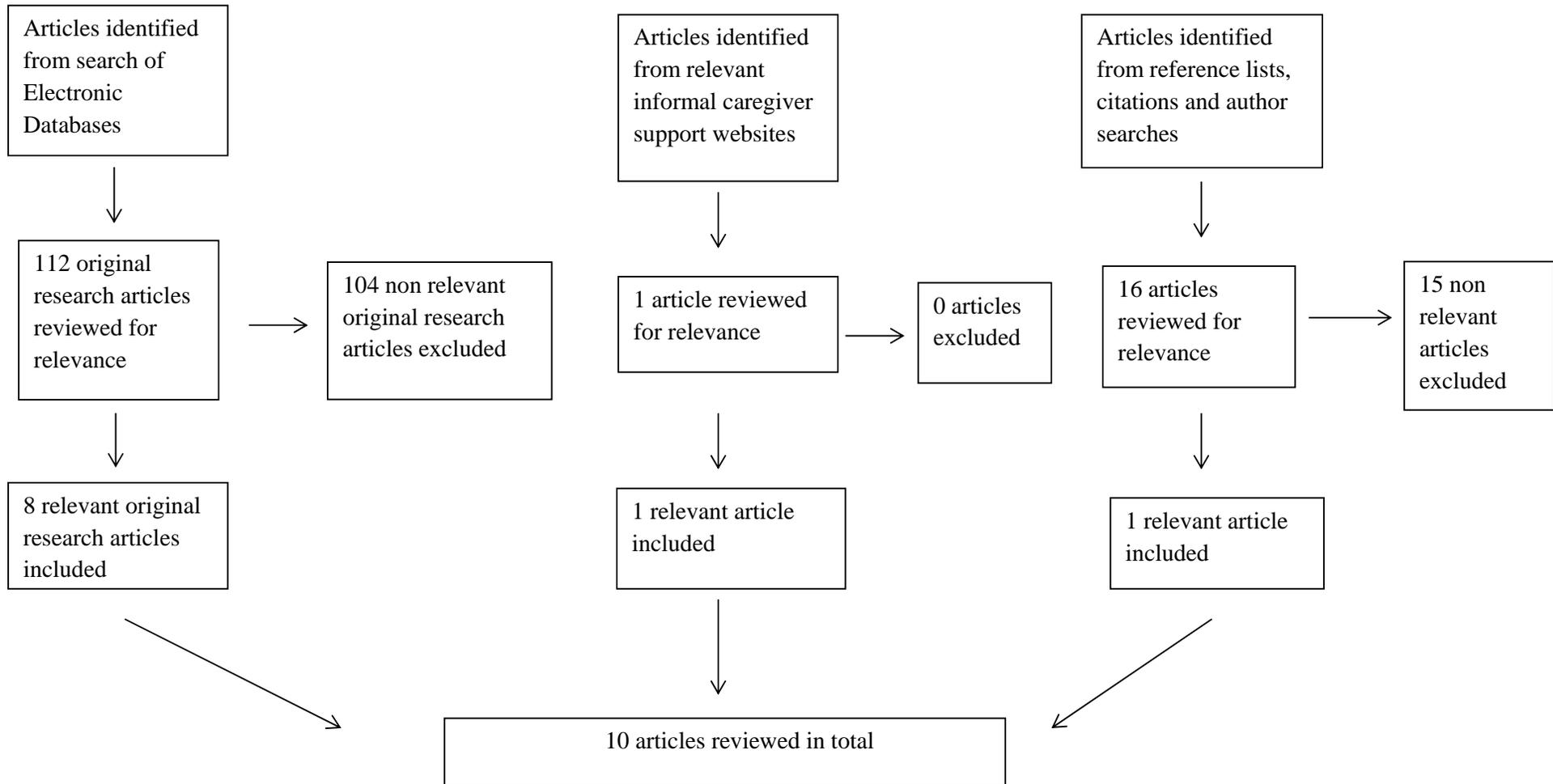


Table 1 Summary of research articles

PLWD: People Living With Dementia AD: Alzheimer’s Disease

Author/Year	Purpose	Sample	Data collection methods	Data analysis	Salient Findings
Travis et al. 2000 USA	To understand how informal caregivers of older adults manage medication for dependent older adults.	23 Informal caregivers of older adults attending adult day care centres. Participants included 22 (96%) female caucasians.	Semi structured individual interviews, caregiver questionnaire, researcher designed medication administration checklist and field notes.	Qualitative data was analysed using HyperResearch software and hand coding for content analysis.	Caregivers described 122 medication management 'hassles' which were classified into three domains: scheduling logistics, administration procedures, safety issues.
Smith et al. 2003 UK	To report the number and type of problems experienced by informal caregivers when managing medications for older care recipients.	184 informal caregivers collecting medications from Community Pharmacies in the UK for older adult care recipients aged >60yrs. Participants included 151 (83%) Caucasians, 113 (61%) of which were female.	Cross sectional structured individual interviews including both closed and open ended questions, as well as a validated Caregiver Strain Index.	Closed ended questions were analysed using Chi-squared and Spearman's rank correlation coefficient analysis. Open ended questions were thematically analysed.	67% of informal caregivers reported problems with one or more medication management activities including problems with medication supply, administration, making clinical judgements and communicating with care recipients/health professionals.
Cotrell et al. 2006 USA	To examine the relationship between care recipient cognitive status and medication management skills, informal caregiver ability to predict care recipient medication management deficits and corresponding caregiver medication management activities.	47 dyads of informal caregivers and their care recipient; including 27 care recipients diagnosed with AD and 20 care-recipients without AD.	Quantitative and qualitative methods were used. Quantitative methods included a survey of care recipients using validated measures; the Medication Complexity Index, the Drug Regimen Unassisted Grading Scale and the Dementia Deficits Scale, as well as a base line and follow-up pill count. Qualitative methods included semi structured interviews with informal caregivers.	Quantitative data was analysed using descriptive statistics, as well as independent and dependent <i>t</i> tests. Qualitative interview data was analysed using content analysis.	The majority of informal caregivers of care recipients with AD (85%) provided assistance with managing medications, as compared to only 30% of those caring for people without AD. Informal caregivers accurately predict care recipient's medication management abilities and adherence rates. Assistance level is associated with cognitive impairment rather than regime complexity. Success of medication adherence interventions varied.
Francis et al. 2006 UK	To explore partnerships between older people and their informal caregivers in the management of medication.	47 dyads of informal caregivers and their older adult care recipients aged >60yrs contacted via Community Pharmacies in the UK. All participants (100%) were caucasian, the majority of which 26 (55%) were female.	Qualitative data collection methods included secondary analysis of semi structured individual interviews.	Qualitative data was analysed thematically using NUD*IST software.	Responsibility for medication management is shared between the care recipient and informal caregiver and varies over time.
Duane et al. 2011 Australia	To develop an understanding of the experiences of non-English speaking older people and informal caregivers in managing their own or a relative's medicines.	22 participants; 12 Non-English speaking adults (> 65years) and 10 Non- English speaking informal caregivers who were clients of Community Ethnic support agencies. Participants were from several different ethnic origins which included Chinese, Vietnamese, Macedonian, Croatian, Italian and Greek.	Qualitative data collection methods included semi-structured individual interviews conducted in the participants native language.	Qualitative data was analysed thematically using Nvivo 8 software.	Participants experienced more complex medication management needs than non-ethnic minority members of a comparative study (While <i>et al.</i> 2012).

Author/Year	Sample	Data collection	Data analysis	Salient Findings	
Kaasalainen et al. 2011 Canada	To explore the personal experiences related to medication management of PLWD, their informal caregivers and assisting health professionals.	57 English speaking participants which included 20 informal caregivers recruited through health services and Alzheimers Society, 11 PLWD, 10 nurses, 10 pharmacists and 6 physicians.	Qualitative data collection methods included semi-structured individual interviews using a grounded theory approach.	Qualitative data was analysed using open, axial and selective coding to identify emerging theory. Nvivo software used.	Processes of medication management vary with the care recipient's level of cognitive decline. Facilitators and challenges to good medication management for PLWD are described, including reasons why informal caregivers assume responsibility for medication management.
While et al. 2012 Australia	To examine the perspectives of PLWD and their informal caregiver regarding their medication management experiences.	17 participants; 8 PLWD were contacted via the Royal District Nursing Service, and 9 informal caregivers were contacted via Alzheimer's support groups.	Qualitative data collection methods included semi-structured individual interviews using a grounded theory approach.	Qualitative data was analysed using Nvivo 8 software for constant comparative thematic data analysis.	Informal caregiver medication management roles change over time as the PLWD's cognition declines. Caregiver burden is significant in relation to this domain of care. Even though a variety of skills and tools are needed for this caregiver role, no training is provided.
Reinhard et al. 2012 USA	To describe the experiences of informal caregivers who perform medical/nursing tasks including medication management in the community setting for adults with multiple chronic conditions.	1677 informal caregivers of adults, (mean age of care recipient 71 years) randomly recruited from research firm database which included 73% Caucasians, 10% African Americans, 9% Hispanics, and 7% other. 58% female.	Investigator developed, population based online survey.	Descriptive statistics.	36% of informal caregiver respondents reported assisting with various medication management tasks. Of these, 47% stated they had received no training to manage medications.
Thorpe et al. 2012 USA	To examine potentially inappropriate medication use and to identify informal caregiver factors related to potentially inappropriate medication use by PLWD.	566 dyads of informal caregivers and their PLWD care recipient, who were contacted via various community health services. Participants included were 67% caucasian, 17% African American, and 16% Hispanic.	Quantitative secondary analysis of data from REACH study (Schulz <i>et al.</i> 2003), measured against the 2003 Beers criteria of medication suitability.	Quantitative data was analysed using STATA 11.0 software for statistical data analysis of association between independent variables.	PLWD were at increased risk for potentially inappropriate medication use if their spouse and/or hispanic caregiver also used potentially inappropriate medication.
Erlen et al. 2013 USA	To describe informal caregiver medication management in community living care recipients with cognitive decline.	91 dyads of informal caregivers and their PLWD care recipient were contacted via geriatric practices, memory clinics, targeted mailing lists, and flyers. Participants included were 85% Caucasian, 10% African American, 1% Asian, and 4% from mixed races. The majority of the participants (70%) were female.	Quantitative data included secondary analysis of baseline data from RCT of informal caregiver responses using 10 validated measures and an investigator developed Medication Reconciliation Form, as well as the cognitive assessment of the PLWD care recipient.	Quantitative data was analysed using SPSS version 20.0 software, descriptive statistics, two sample <i>t</i> tests, Mann-Whitney <i>U</i> tests, regression analysis, Spearman's rank-order analysis and Pearson product-moment correlations.	Informal caregivers find medication management challenging and burdensome. The caregiver's age, cognitive ability, depressive symptoms and perception of their care recipient's behavioural problems can impact on their medication management. Assessing medication management deficiencies requires measuring a number of factors.