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Abstract

This paper outlines the motivation for and the development of a medication management information resource for Australian ethnic minority informal caregivers of people living with dementia. The aim of this project is to enable ethnic minority informal caregivers to safely and effectively manage medications for their care recipient living with dementia in the community setting. A large number of Australian informal caregivers of people living with dementia are from ethnic minority backgrounds. Medication management is a common, but often times complex, daily task undertaken by many informal caregivers. Since many of the caregiver's medication management responsibilities increase as the cognitive capabilities of their care recipients' decline with advancing dementia and no comprehensive dementia specific medication management information resource currently exists we felt it important to develop a useful, accessible information resource for informal caregivers in this role. The development of this medication management information resource occurred in two stages; the first stage involved a qualitative study to gain insight into the perspectives and the information needs of these ethnic minority informal caregivers as they manage medications for their care recipient. The results and main themes identified in this first stage were then used to inform the second stage of the study which involved the development of the medication management information resource, to be available online in both English and Italian. These are nearing completion and will be evaluated before becoming generally available online. It is anticipated that this information resource will provide family caregivers of people with dementia information and support in this role.

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DEVELOPING A MEDICATION MANAGEMENT RESOURCE FOR ETHNIC MINORITY INFORMAL CAREGIVERS OF PEOPLE LIVING WITH DEMENTIA

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Abstract

This paper outlines the motivation for and the development of a medication management information resource for Australian ethnic minority informal caregivers of people living with dementia. The aim of this project is to enable ethnic minority informal caregivers to safely and effectively manage medications for their care recipient living with dementia in the community setting.

A large number of Australian informal caregivers of people living with dementia are from ethnic minority backgrounds. Medication management is a common, but often times complex, daily task undertaken by many informal caregivers. Since many of the caregiver's medication management responsibilities increase as the cognitive capabilities of their care recipients' decline with advancing dementia and no comprehensive dementia specific medication management information resource currently exists we felt it important to develop a useful, accessible information resource for informal caregivers in this role.

The development of this medication management information resource occurred in two stages; the first stage involved a qualitative study to gain insight into the perspectives and the information needs of these ethnic minority informal caregivers as they manage medications for their care recipient. The results and main themes identified in this first stage were then used to inform the second stage of the study which involved the development of the medication management information resource, to be available online in both English and Italian. These are nearing completion and will be evaluated before becoming generally available online. It is anticipated that this information resource will provide family caregivers of people with dementia information and support in this role.

Rationale

In Australia, the number of informal caregivers of people living with dementia (PLWD) and residing in the community setting is growing (AIHW, 2012). It has been estimated that the 298,000 Australians living with dementia in 2011 will increase to 400,000 by 2020 (AIHW, 2012), which suggests that the number of informal caregivers of PLWD will also grow. Given Australia's multicultural heritage, a large number of informal caregivers and community dwelling PLWD are from ethnic minority backgrounds. A 2009 national survey of disability, ageing and carers recorded that 24% of PLWD were born in countries outside Australia. This diverse group of PLWD were more likely to be cared for at home, by their relatives, making up 33% of the community-dwelling PLWD (ABS, 2010; AIHW, 2012).

Medication management is a daily task carried out by the majority of informal caregivers of PLWD. A recent US based study estimated that 54% of informal caregivers manage medication during the earlier stages of their care recipient's dementia. This increases to 90% reporting medication management responsibilities as the care recipient's cognitive decline increases in the later stages of dementia (Thorpe, Thorpe, Kennelty, Gellad, & Schulz, 2012). This care management role is important as it helps to improve health outcomes for the care recipient (Arlt, Linder, Rosler, & von Renteln-Kruse, 2008). However it may lead to caregiver stress because it often requires considerable knowledge to undertake correctly and effectively (Carter, Moles, White, & Chen, 2013). For example, informal caregivers are often expected to undertake many of the following medication management roles without any formal training (Brodaty & Green, 2002; Smith, Francis, Gray, Denham, & Graffy, 2003; Travis, Bethea, & Winn, 2000):

- administering multiple medications according to appropriate schedules (sometimes against the care recipient's wishes) in a safe and effective manner;
- avoiding medication errors and possible drug interactions;
- providing feedback to health professionals regarding the medication's effectiveness and/or side effects;
- sometimes making judgements regarding when to withhold, increase, decrease or discontinue a medication;
- maintaining continuous supplies of medications and communicating with both the care recipient and health care providers about medications;
- checking prescriptions for accuracy and querying changes in medications;
- granting or refusing consent for newly prescribed medications on behalf of the care recipient who is no longer able to make these decisions.

Other important factors identified in the literature which contribute to the stress and complexity of this role include unhelpful health systems and practices which are difficult to negotiate (Francis, Smith, Gray, & Denham 2006; Smith et al., 2003) and a lack of information available for this role (Reinhard, Levine, & Samis, 2012).

In addition to these multiple medication management roles regularly undertaken by informal caregivers of PLWD, Duane, While, Beanland, and Koch (2011) describe further medication management roles which are assumed by ethnic minority informal caregivers. These include: accessing health care providers who speak the same language and/or providing culturally appropriate services; acting as interpreters and/or accessing interpreter services; and, where possible, accessing relevant translated medication information.

Given the complexity of the medication management role, the lack of information available to informal caregivers, and the likely additional difficulties facing some ethnic minority informal caregivers to undertake their roles safely and effectively, this exploratory research study was undertaken in two stages. The aim of the first qualitative stage was to gain insight into the perspectives and the information needs of Illawarra based ethnic minority informal caregivers as they manage medications for their care recipient living with dementia. The results and main themes identified in this first stage were then used to inform the second stage of the study which involved the development of the medication management information resource, to be generally available online in both English and Italian.

Stage 1: Qualitative phase

Methods

This first stage of the study was carried out over a four-month period from July to October 2012. Potential participants from a number of ethnic minority backgrounds, representative of the largest groups of older adults in the Illawarra from non-English speaking countries (Broadley, Mihajlovic, Paschalidis-Chilas, & Perry, 2009), were contacted and invited to take part in the study via local informal caregiver support groups, via word of mouth, or via contacts known to the research team. Qualitative methods, including three focus groups and seven individual one-on-one interviews, were used for data collection purposes. The focus group and interview questions included six open-ended questions, developed by the research team, that were informed by evidence in the literature and addressed the research aim. The questions covered informal caregiver medication management experiences, medication information sources currently used by informal caregivers, and the most preferred content and/or format for any future information resources to be produced. Verbal responses to the focus groups and one-on-one interviews were transcribed verbatim and thematically analysed by three independent qualitative researchers.

Results

Tables 1 and 2 summarise the demographic data of the 22 focus group participants and the seven one-on-one interview participants from six different ethnic minority groups who participated in the study. The majority of these participants (26 out of 29) were female informal caregivers.

Table 1

Demographic Data for Focus Group Participants

Nationality	Number of Caregivers	Gender	Carer Status
Italian	6	All female	Spouse caregivers
Macedonian	11	8 female, 3 male	Spouse caregivers
Portuguese	5	All female	4 spouse caregivers, 1 adult child caregiver

Table 2

Demographic Data for Semi-structured Individual Interview Participants

Nationality	Number of Caregivers	Gender	Carer Status
Italian	2	Female	Adult child caregivers
Greek	2	Female	1 adult child, 1 spouse caregiver
Dutch	1	Female	Spouse caregiver
Croatian	1	Female	Adult child caregiver
Macedonian	1	Female	Adult child caregiver

The key themes identified in this first stage of the study describe the informal caregiver's medication management role as a source of stress, especially as their care recipient's cognitive abilities started to decline.

"We were finding too much on the floor, not only from hers but also from his. And there were occasions when he was taking hers. He took her medication instead of his. Oh it was just horrendous, it was just horrendous" (Greek adult child caregiver)

They also suggested that their medication management role often led to conflict between themselves and their care recipient as they tried to limit the care recipient's autonomy over medication management and/or tried to get their care recipient to be more compliant with taking their medications.

"He just says 'oh don't worry about it (the medication) its Ok, it's under control' cause I'm not allowed to take control" (Dutch spouse caregiver)

"She's decided that when Dad is trying to give her the medication he's trying to poison herand that's when she would have the biggest tantrums" (Italian adult child caregiver)

For these reasons, the informal caregivers often adopted strategies such as supplying medications in medication aides (e.g., blister packed medications), and hiding (sometimes crushed medications) in their care recipient's food.

The participants in this first stage of the research study suggested that even though they were currently accessing medical practitioners, community pharmacists, caregiver support groups and the internet for

their medication information needs, they felt that many of their information needs remained unmet. They maintained that there was a lack of access to appropriate medication information in any format, visual, verbal or written. They also suggested that the limited information currently available did not always cater for those with diverse literacy levels and was certainly not always available in different languages.

“I go to a chemist where there is a Portuguese girl. We understand each other. It’s the other ones I can’t understand a word. I like to go in when she is working but she only works one day a week”
(Portuguese spouse caregiver)

Stage 2: The development of the medication information resource

In addition to using the themes identified in the first qualitative stage of the study, we conducted a review of current paper-based and online medication management information resources available for informal caregivers of PLWD within Australia to inform the development of a medication information resource. Material was sourced from a variety of providers including the Australian Government, Alzheimer’s Australia, the National Prescribing Service, community pharmacy help-sheets, the Royal District Nursing Service, Independent Living Centres and Carers Australia. This review found that medication management information for informal caregivers is fragmented, not comprehensive and difficult to access. Of this material, only selected information resources are currently available in various community languages.

The findings from both stages were used to guide the development of a comprehensive, medication management information resource for informal caregivers of PLWD. This resource addresses issues specified by the informal caregivers as being important during stage 1 and also provides links (where appropriate) to the additional information currently available from the aforementioned providers. To ensure that the information is easy to read and understand, health literacy guidelines (US Department of Health and Human Services, 2009) were used to help develop the resource and visual, written and audio content were included. In addition, the clarity and usefulness of the written English content was pretested with a small number of informal caregivers and health professionals before having the material translated into Italian.

Evaluation of both the English and Italian versions of the online resource is currently underway to ensure its usability and relevance to informal caregivers before making the resource generally available online. An adapted version of the ‘Quality checklist for reviewing health information’ (Centre for Health Promotion, 2006) is being used to structure the evaluation process. It is anticipated that further languages and other formats such as a DVD version will become available to improve the accessibility of the resource in the not too distant future.

Summary

This information resource will provide ethnic minority informal caregivers of PLWD accessible, easy to understand information which should be able to support them in their medication management roles. Health professionals will also be able to access and recommend this information resource for their ethnic minority patients living with dementia in the community setting and their informal caregivers. Overall it is anticipated that this resource will help ethnic minority informal caregivers to continue to provide safe and effective medication management for their care recipient living with dementia.

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