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Keywords

Community, dementia, ethnic minority, family caregiver, medication management

Disciplines

Medicine and Health Sciences | Social and Behavioral Sciences

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Abstract

This qualitative study explored the medication management experiences of Australian ethnic minority family caregivers of people living with dementia. From the perspective of this group of caregivers, medication management was a source of stress resulting from the progressive loss of ability of care recipients to manage their own medications; the complexity of the medication regime and the caregiver's lack of trust of the care recipient to safely and effectively manage medications. Caregivers used various strategies to manage medications and avoid conflict with care recipients including being watchful and involving other family members in medication management tasks. Family caregivers indicated that a lack of information and access to support to inform their medication management role added to their stress, which was exacerbated in some cases by limited English proficiency. Supportive factors noted by caregivers included a well-established relationship with a community pharmacist, involvement of a geriatrician, family support and caregiver support group participation.

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Introduction

Based on projections of population and ageing, the 298,000 Australians estimated to have been living with dementia in 2011 will increase to 400,000 by 2020 (Australian Institute of Health and Welfare (AIHW) 2012a). In Australia, family caregivers are vital to the provision of care as more than 70% of older adults living with dementia reside in a community setting (AIHW 2012a). Further, a disproportionately large number of these community-dwelling people living with dementia are from ethnic minority backgrounds. A 2009 national survey of disability, ageing and carers recorded that 24% of people living with dementia were born in countries outside Australia or other English speaking countries of origin, however this group were more likely to be cared for at home, making up 33% of community-dwelling people living with dementia (Australian Bureau of Statistics 2010; AIHW 2012a). The importance of maintaining responsibility for the care of family members at home and negative perceptions of residential aged care facilities are two factors which may account for this reported over representation of ethnic minority people living with dementia in the community setting (Berisic & Nesvabda 2008).

Providing care for people living with dementia in the community comes at a considerable cost to family caregivers, who are likely to spend more than 40 hours per week providing many different care roles (AIHW 2012a), including medication management (Fortinsky 2001; Brodaty & Green 2002; Boughtwood, Adams, Shanley, Santalucia & Kyriazopoulos 2011).

Medication management is an important part of the family caregiver's role, helping to improve health outcomes and reduce hospitalisations for the care recipient living with dementia (Arlt, Linder, Rosler & vonRenteln-Kruse 2008). As the care recipient's ability to safely and effectively manage their medications deteriorates, family caregivers, when

available, assume greater responsibility for medication management (Cotrell, Wild & Bader 2006, Kaasalainen et al. 2011), from a baseline of approximately 54% to over 90% being involved with medication management in the later stages of dementia (Thorpe, Thorpe, Kennelty, Gellad and Schultz 2012). This care management role requires clinical skills and knowledge, especially since medication regimes for the care recipient are often complex and the needs of the person living with dementia change with disease progression (Duane, While, Beanland & Koch 2011).

Medication management is a broad concept that involves many key players, including the care recipient, the caregiver (when appropriate) and often times multiple health care providers (While, Duane, Beanland & Koch 2012). From a family caregiver's perspective, medication management includes maintaining continuous supplies of medications, assisting with administration, making clinical judgements and communicating with health care providers and care recipients (Smith, Francis, Gray, Denham & Graffy 2003). Brodaty and Green (2002) note that this involves being informed about what is prescribed, asking relevant questions of health care professionals, monitoring for medication adherence, watching for medication-related side effects and granting or refusing consent for medications where the care recipient is no longer able to give this.

Despite these complexities, medication management remains an under researched topic. While general studies of medication management by family caregivers of older adults are available (Travis, Bethea & Winn 2000; Smith et al. 2003; Travis et al. 2003; Francis, Smith, Gray & Denham 2006), few studies have focused exclusively on family caregivers of people living with dementia (Cotrell et al. 2006, Kaasalainen et al. 2011, While et al. 2012). In particular, studies of the medication management experience of ethnic minority family

caregivers have been neglected, despite knowing that this group generally encounter more difficulties when accessing health services and information (CIRCA 2008) This present exploratory study aimed to remedy this situation by exploring the views of ethnic minority family caregivers of people living with dementia and their medication management experience including the adequacy of their access to medication management information and support

Method

Design

A qualitative methodological approach was chosen in order to gain an understanding of the day to day medication management experiences of family caregivers of people living with dementia This methodological approach was deemed appropriate to encourage the sharing of details that describe the context of this issue, allowing it to be understood with more clarity, making sense of choices, behaviours, beliefs and values (Bryman 2008) and to further explore a topic about which little is known (Carey & Asbury 2012).

Following ethics approval from the University of Wollongong Human Research Ethics Committee, three focus groups and seven semi- structured individual interviews were conducted in the Illawarra, a multicultural urban area, south of Sydney, Australia. A set of six relevant questions were used as a guide for both the focus groups and the individual interviews beginning with a general question asking about the sorts of issues the family caregiver(s) might have encountered related to their relative's medications. Other questions asked about the sources of information they accessed for guidance with their relative's medication(s).

Participants

A purposive sample of ethnic minority family caregivers of people living with dementia who were likely to have first-hand experience of managing medications was gathered from volunteers. These were contacted through various locally based government multicultural health services and non-government run community family caregiver networks such as Alzheimer's Australia and through contacts known to the research team. The majority of the focus group participants were spouse caregivers while the majority of individual interview participants were adult child caregivers.

Difficulties were encountered enlisting participants which may have resulted from specific cultural perceptions relating to caregiving and dementia. For example, family caregivers may not identify as caregivers as this role is perceived to be a normal part of family responsibility (Berisic & Nevsbda 2008). In addition, dementia is viewed with considerable stigma across many ethnic minority communities (Berisic & Nevsbda 2008), and as such caregivers may have been reluctant to volunteer and participate in the study.

The following tables (1 and 2) summarise the demographics of both the focus group and the one-on-one interview participants.

Table 1. Focus groups

Nationality	Number of caregivers	Gender	Carer status
Italian	n=6	all female	spouse caregivers
Macedonian	n=11	8 female/3male	spouse caregivers
Portuguese	n=5	all female	4 spouse caregivers/ 1 adult child caregiver

Table 2. Semi-structured individual interviews

Nationality	Number of caregivers	Gender	Carer status
Italian	n=2	female	adult child caregivers
Greek	n=2	female	1 adult child/ 1 spouse caregiver
Dutch	n=1	female	spouse caregiver
Croatian	n=1	female	adult child caregiver
Macedonian	n=1	female	adult child caregiver

Procedure

All focus groups were conducted at the normal meeting time and place of each specific ethnic minority caregiver support group. Their regular trained interpreter was used for translation as necessary. All semi structured interviews were conducted at times and places convenient for the family caregivers. Data were collected over a four month period from July-October 2012. Focus group and interview discussions were audio recorded and transcribed verbatim.

Analysis

Transcribed data from focus group and interview discussions were hand coded and closely reviewed by three members of the research team to identify patterns of meaning using a thematic analysis technique (Braun & Clarke 2006). This technique is well suited to capture important meanings across the data set in order to convey the story of the data and present a reasoned and logical argument in response to the research question (Braun and Clarke 2006). The guiding principles of transparency and systematicity as described by Meyrick (2006), were applied to ensure rigour throughout the research process.

Results

The major themes emerging from the study were: managing medication is a source of stress for family caregivers; medication management may be a point of conflict that needs to be carefully controlled; family support of this caregiving role is considered to be extremely important and family caregivers believe that they would benefit from more sources of external information and support regarding medication management. Findings which contributed to these major themes will be described in detail in the following sections.

Medication management is a source of stress for family caregivers

Factors identified that contributed to the stress of family caregivers in their role as medication managers included: the progressive loss of ability of care recipients to manage their own medications; the complexity of the medication regime; the caregiver's lack of trust of the care recipient to safely and effectively manage their medications; and the caregiver's lack of knowledge about the medications prescribed. Caregiver stress was exacerbated in some cases by limited English proficiency

Progressive loss of ability of care recipients to manage or take medications A frequent comment by family caregivers was the noticeable decline over time of the care recipient's

ability to manage their own medication. This occurred as their relative's cognitive loss progressed but in some cases additional physical decline also contributed to medication management difficulties.

Caregivers noticed specific changes in the care recipient's behaviour that resulted in the care recipient experiencing medication management difficulties. These included; no longer remembering to refill scripts, forgetting to take tablets, forgetting instructions from the pharmacist, forgetting why they needed the medication or forgetting the process of how to take tablets. In the majority of cases, during the early stages of the care recipient's cognitive decline, family caregivers organised for their relative's medications to be blister packed by their pharmacist. This then facilitated the management of medication prescriptions and some felt this helped their relative to remember to take their medication.

'...the medication.... he wasn't taking it properly. But now he is taking it regularly ...the Chemist they just fix up the blister packit seems to be excellent.' (Macedonian focus group)

Some caregivers noted that these strategies had worked for a time. Following further cognitive decline they became less useful for the care recipient which then necessitated a more active medication management role by the caregiver:

'Oh well for a little while there, we weren't doing the managing of the medications....but we were noticing that a lot of times, they had blister packs, and a lot of times, the medication was left in the blister pack....and we would find pieces of medicine on the floor' (Greek adult child caregiver)

Caregivers whose relative's cognitive abilities had further declined, noted the care recipient, in many instances, no longer understood the need for all their medications and would either not take any of their medications or would select the ones they perceived were bringing them some therapeutic benefit.

'My husband he remembers, he takes his own medication what he like but he only takes the blood pressure tablets because the other tablets he thinks do not do anything to him so it's no worth to take it.' (Italian focus group)

This concerned family caregivers who worried about the ongoing consequences for the care recipient of leaving serious chronic conditions untreated. Sometimes this refusal to take medications appeared to be based on the care recipient's long held beliefs about the inevitability of health problems in old age and a belief that medications would do little to alleviate these problems;

'So my husband, he didn't accept the medications, he wouldn't take the medications because he always said "what about the old people back in the ages, what did they do and how did they get on without the medications?"' (Italian focus group)

Caregivers who were looking after a relative whose dementia had progressed significantly, noted that their relative had forgotten how to take tablets and no longer swallowed them but chewed them or spat them out and/or began to have altered perceptions about the purpose of the medication(s), sometimes believing for example that the medications were poisonous. In an attempt to improve their relative's medication taking behaviour many caregivers resorted to crushing medications and hiding them in their relative's food.

‘So we started hiding the medication in food, we crushed it... put it in some yoghurt....some of them weren’t crushable so we put them whole into liquorice or something that has a strong taste over powering the other one.’ (Italian adult child caregiver 1)

This was a concern for one caregiver who worried that crushing would change the rate at which enteric coated tablets would be absorbed. Other caregivers who were also crushing tablets seemed unaware that this could potentially pose problems.

In addition to declining cognitive abilities, declining physical capabilities of the care recipient resulted in them not being able to open medication bottles and/or access medication from blister packs. Prior to having their medications managed by their caregiver, some adopted unsafe coping strategies such as putting medications into unlabelled containers with wide lids to assist with maintaining their independence. On such occasions caregivers were concerned that these strategies were confusing and could lead to medication errors:

‘I think she’s starting to have arthritis as well, and she couldn’t open the bottles..... So she put them in vitamin jars ... and I didn’t know what was what.’ (Croatian adult child caregiver)

Complexity of the medication regime The majority of caregivers commented on the large number of medications that their relative took and regarded this as a contributing factor to the care recipient becoming less able to manage their medications without assistance. These regular medications, which needed to be taken multiple times throughout the day, included treatment for other co-morbid chronic conditions such as diabetes, depression, Parkinson’s, arthritis, hypertension and osteoporosis;

‘There’s so many... he was so confused, there were so many medications at the table and different times of the day.’ (Greek adult child caregiver)

This was confusing for both the care recipients and the caregivers.;

‘And he was put on further more tablets. I don’t know what they are for or what they are.’ (Macedonian focus group)

Keeping track of when prescriptions were due and making sure the care recipient had adequate stock levels was also more difficult to manage as a result of the use of multiple medications. Further, the use of many different medication formulations, such as puffers, injections and suppositories added complexity to the caregiver’s role, as did having to give medications with doses that needed adjusting, such as the anti-coagulant Warfarin and Insulin injections.

When not in control of medication, caregivers distrust the care recipient’s ability to manage medication Caregivers whose relatives were still taking responsibility for some or all of their own medication management talked of needing to be constantly watchful to make sure that their relative was managing these tasks well. In the lead up to taking total responsibility for the medication management role, family caregivers suggested that their stress was added to by having to always check-up on their relative’s medication management capabilities, for example assessing the caregiver’s understanding of verbal medication instructions from doctors and pharmacists:

‘I said to him, oh well, explain to me and he said “oh no no no” and I don’t think he could explain it. I think he forgot what the chemist told him.’ (Dutch spouse caregiver)

Family caregivers who had taken control of medication management reflected on the time when their relative was still managing some or all medication tasks as a particularly stressful period:

‘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)

Family caregivers express feelings of disempowerment and use emotive language when describing their medication management role Some caregivers expressed frustration that, despite their desire to manage medications well, they had little power to convince their relative living with dementia to take their medications if they refused to do so;

‘So I got a big problem... because he’s got osteoporosis, he’s got a big lung problem. But he doesn’t want to take it. I can’t do anything...’ (Italian focus group)

Some adult child caregivers avoided introducing change until they felt it would be absolutely necessary as they knew these changes would be unlikely to be accepted and may well be met with anger or be challenged.

‘If she can’t open the bottle, its very frustrating. My sister and I we discussed eventually we will arrange blister packs for her but she really doesn’t want to do thatshe likes things the way she’s always done them.’ (Croatian adult child caregiver)

Similarly, the medication management actions of some female spouse caregivers were rejected by their husbands who refused to accept their wives’ attempts to intervene. The advice of respected outsiders, such as doctors was still held in high regard by care recipients.

‘He does do what a doctor tells him...I’m his wife! Who am I!? And he is the head of the house. And the doctor he knows so much more than I!’ (Dutch spouse caregiver)

Lack of knowledge about prescribed medications Caregivers often made comments indicating that they had not been given information from the healthcare providers about the medications their relative was taking. While some caregivers did not seem concerned, others worried that they did not understand why each medication had been prescribed and the consequences of taking so many medications:

‘Mum’s on 12 or 10 or something and its just such a chemistry set inside a body and how it reacts with Mum is so different to how it might react to someone else and so how can they get it right?’ (Italian adult child caregiver 1)

More information about the side effects and potential adverse reactions associated with taking different medication was requested by many of the caregivers. For example, one caregiver stated she was unaware that constipation was a side effect of her relative’s medication, which she could easily have addressed by making changes to her relative’s diet.

Language barriers including low English literacy Limited English proficiency was an additional source of stress encountered by some spouse carers, as compared to adult child family caregivers, which made their medication management tasks more complicated. In an attempt to minimise this stress, many tried to access pharmacists/pharmacy assistants and or doctors that spoke their own language, even if that meant travelling some distance or waiting a few days;

‘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 focus group)

When this was not possible, some relied on extended family or neighbours to interpret for them or where possible, accessed an interpreter service. This also included translating or clarifying written information from medication information leaflets written in a level of English beyond the literacy level of the caregiver. One Italian adult child caregiver talked of such assistance that she gave to her father who was the primary caregiver for her mother:

‘His English is pretty good (spouse caregiver) and he’ll read it and he’ll go ‘I think I’ve got the gist of it but I’m not really sure what this is about’ and we will read through it together.’ (Italian adult child caregiver 1)

Progressive cognitive loss resulted in some care recipients losing the ability to converse in English. This resulted in a further complication encountered by some adult child caregivers who were not always fluent in the language of origin of their care recipient.

‘He has reverted all the way back to his own language so I need my husband to say “These are your tablets” in Macedonian.’ (Macedonian adult child caregiver)

Medication management may be a point of conflict that needs to be carefully controlled

Medication management tasks were frequently mentioned as a source of conflict between caregivers and care recipients. Caregivers talked of conflict, mostly in the form of verbal outbursts resulting from their relative valuing continual autonomy in this area.

‘When we got the blister packs he was so angry with us he said “what do you think!? Do you think I can’t manage medications!?”’ (Greek adult child caregiver)

Conflict over medication management decisions often coincided with the care recipient’s denial of dementia or the extent of their dementia, holding to the belief that their forgetfulness was a normal part of growing old:

‘It’s very frustrating trying to explain to her that her memory is not as good as she thinks and yeah making sure that she’s got all her medications....One time I did frankly tell her what she had (dementia) and she basically told me off and she told me “One should never say that especially to her own mother!”’ (Croatian adult child caregiver)

Caregivers who tried to take control of various tasks in these contexts were often not successful:

‘So we decided to take the blister packs away from him.... then my father-in-law would get really agitated and say you know “you’re taking away my responsibility” And so in the end ... we took them back. We just couldn’t handle it anymore and we let him do it.’ (Greek adult child caregiver)

Caregivers who were able to avoid conflict and introduce changes in medication management adopted a strategy of managing medications from a distance by being watchful, checking and enlisting the help of other people who were respected by the care recipient, such as doctors, to negotiate needed changes. They also spoke with their pharmacist to alert them of their relative’s dementia and cognitive decline. They worked closely with them to keep track of prescriptions and manage dispensing of extra prescriptions, often obtained when the care recipient visited doctors other than their regular doctor, and over the counter medications:

‘Fortunately we had a relationship with the pharmacist and she’d ring and say “look he’s come in with this particular script” and we’d say ‘no, you don’t fill it.’ (Greek adult child caregiver)

Family support of this caregiving role is considered to be extremely important

Additional family support was mentioned frequently by family caregivers with regard to their medication management roles. Families would share medication management tasks with particular roles designated to different members;

‘Usually one of us will try and get her to the doctors and one of us will take her to the chemist to pick up her scripts.’ (Italian adult child caregiver 2)

Spouse caregivers in particular, talked of enlisting the help of other family members including their adult children to try to give tablets when their relative was refusing to take them. They also often asked their children to check or access information about medications, especially when they had limited English reading skills.

Family caregivers believe that they would benefit from sources of external information and support regarding medication management

Doctors were frequently mentioned by caregivers as the primary source of medication information. In some cases however, caregivers felt that doctors did not always inform them of changes to medications resulting in confusion;

‘But he said ‘Dr’s given me one a little bit different’I’ll go and see Dr S about it next time.....I don’t know why, maybe he has given him something a little bit stronger.

‘(Dutch spouse caregiver)

Caregivers were especially appreciative of the proactive efforts of geriatricians to review their relative's medications and in many cases reduce the number of prescribed medications. They expressed relief at having to manage fewer daily medications for their relatives. Unfortunately not all caregivers had access to geriatricians as a result of the way in which Australia's health system is structured such that a person's first contact is through a General Practitioner doctor who may choose to continue to treat a client with dementia and not refer on to a geriatrician (AIHW 2012b).

Family caregivers who had been long-term customers at one pharmacy reported good access to medication information and support for their medication management role. Few caregivers however, were offered information about blister packs or provided with medication lists for their relative even when the pharmacist was aware that they were caring for someone with dementia. Several commented that in some pharmacies, where the only contact was with pharmacy assistants, they were unable to identify or access the pharmacist to ask for medication information:

'The one that we had in 'D' that man knew you because we had been going there for so many yearsthose people up there...there are different people up there all the time and I don't even know who is the owner or who is the pharmacist.' (Dutch spouse caregiver)

Adult child caregivers were most likely to access the internet for medication information. Some were concerned that there was no way of knowing if the sites they were accessing were trustworthy. Reasons given for seeking information on the internet varied and included; convenience, researching complementary treatments, checking on medication side effects and searching for any medication information, where none had been provided.

Support groups specific to ethnic minority family caregivers were an additional source of medication information especially for the focus group participants. These groups were conducted in the relevant languages and therefore provided an important opportunity for caregivers to access information and support from their peers.

Discussion

Several findings from this current study concur with previous research concerning family caregivers and their medication management role for older adults with chronic illnesses, encompassing those with dementia. These include the complexity of the process of medication management, the reporting of stress related to this caregiving role, strategies adopted by family caregivers as they manage medication and the lack of adequate medication management information and support available to family caregivers in this role (Travis et al. 2000, Smith et al 2003, Cotrell et al 2006, Kaasalainen et al 2011). Importantly this current study highlights additional details of the experience of ethnic minority family caregivers in their medication management role caring for a person with dementia.

Key new findings elaborate on the lack of access to appropriate medication management information in any format, visual, verbal or written, including material which is language specific. This finding points to another key aspect of this research; some caregivers require resources to be provided in their own language, preferably in a visual format, others are literate in English only, while a further group are bilingual. This research strongly suggests that diversity within ethnic minority groups needs to be recognised. This evidence of diversity within ethnicity concurs with the argument presented by Iliffe and Manthorpe (2004) who suggest that diversity within ethnic groups is evident and is influenced by other factors such as such as education, socio-economic status and the impact of immigration. Finally, the

findings highlight the crucial support roles of family, doctors, community pharmacists and carer support groups.

The difficulties of managing complex medication regimes were mentioned frequently in other medication management studies (Francis et al 2006, Cottrell et al 2006 & Kaasalainen et al. 2011). In this study, family caregivers valued de-prescribing of medications by doctors and specialists with the aim of reducing regime complexity. In addition, family caregivers initiated other strategies to assist their family member to manage complex daily medication schedules, including the use of calendars, dosette boxes or blister packaged medications. It is important to note that some participants in this study reported frequent care recipient medication management errors while using blister packed medications. This has not been noted in previous research. This suggests the need for ongoing review of the usefulness of this strategy, as cognitive decline progresses.

Caregiver stress associated with medication management roles was commonly reported in other qualitative studies (Travis et al. 2000, Francis et al. 2006, Kaasalainen et al 2011, While et al.2012). The current study confirmed this finding indicating that stress is associated with this role regardless of the ethnicity of the caregiver. These findings elaborate however, on the increased stress resulting from the progressive cognitive decline of the care recipient.

An important contributor to caregiver stress was the level of conflict surrounding the medication management role. This has also been reported in other research (Kaasalainen et al. 2011, While et al 2012). Our evidence suggests that there are two sources of conflict. Conflict arose between the care giver and the care recipient as the care recipient tried to maintain autonomy over medication management tasks or conflict arose when care recipients refused to take medications in a compliant manner.

Family caregivers in this study often reported crushing medications and hiding them in foods as a strategy to manage medications which the care recipient refused to take. Most of them seemed to be unaware of the fact that crushing some medications may alter the formulation potentially resulting in increased toxicity, decreased efficacy and/or making the medication unpalatable or unstable (Paradiso et al. 2002). As noted, only one family caregiver in the present study was aware that crushing medication was not always safe. This finding illustrates the need for additional information to be provided to family caregivers to inform them of safe and effective strategies to manage medications which the care recipient refuses to take.

Most participants were dissatisfied with the available medication information sources and resources for ethnic family caregivers of people with dementia. Family caregivers often talked of having to initiate requests for medication information from pharmacies and doctors. Other studies indicate that this problem is faced by family caregivers despite their ethnicity, for example one fifth of family caregivers in Donelan et al's. (2002) study stated they received no information to assist them in administering multiple medications to their care recipients. Furthermore, literature reviews conducted by Kralik et al's. (2008) and Washington et al. (2011), suggested that extensive unmet caregiver information needs persist. Unfortunately, the findings from this current study suggest that little has changed in response to these earlier findings, regarding the timely and appropriate supply of medication management information to family caregivers.

This lack of access to medication information and resources was made more difficult for some caregivers in this study who faced language barriers. These results are similar to other studies which documented this additional burden for ethnic minority family caregivers

(Berisic & Nesvabda 2008; Duane et al. 2011). Notably, not all participants in the current study faced this difficulty. Adult children and spouse caregivers participating in the individual semi-structured interviews did not mention that language barriers posed a difficulty for them because they were all literate in English. However, the majority of spouse caregivers who participated in the focus group were less literate in English. They stated that they needed to access interpreter services or bilingual doctors and pharmacists/assistants to discuss medication management issues. Alternatively, when these services/resources were not available, which was often the case, they were reliant on adult children or friends to translate written or verbal information for them.

These same spouse caregivers found that on the few occasions when written information was provided to them, it was written at a level which was difficult for them to read and understand. These findings are supported by Weih et al. (2008), who found that the readability of information sheets, related to dementia, produced in European countries had a mean readability of high school/college level, which is likely to be outside the understanding of most family caregivers from ethnic minority backgrounds. For these reasons it is important, when providing written information to family caregivers, especially to those from ethnic minority groups, that it be available in a simple, easy to read format, or in alternate formats, such as DVD visual presentations (Reinhard & Choula 2012).

Unlike most spouse family caregivers in the current study, the adult child family caregivers were more likely to be proficient in terms of being able to read and understand medication information. However, since in several cases the information provided was scarce and/or non-existent, some of these younger caregivers searched the internet for information about medication management. Unfortunately, searching the internet has its limitations, because

as mentioned some did not know if the medication information they accessed on the internet was trustworthy, which is also documented in the evidence (Marshall & Williams 2006). These findings suggest that younger caregivers may need to be guided to information on the internet which is from a reputable source. Not all family caregivers are likely to have the equipment and technological skills to effectively access and search the internet (Mastel-Smith & Stanley-Hermanns 2012) so it remains important to continue to provide information available in other formats.

Extended family involvement in caregiving roles has been previously reported (CIRCA 2008; Boughtwood et al. 2011; Lin, Macmillan & Brown 2011). This study describes that involvement in relation to the medication management role of caregivers and was a key new finding of this study. This has implications for healthcare professionals who may need to discuss medication management information with all family caregivers involved in the role, especially when dealing with individuals from ethnic minority backgrounds.

Other healthcare providers such as general practice doctors, specialists, nurses and community pharmacists, particularly those who were bilingual, provided valuable external support for family caregivers in this study. Caregivers, who had good long term relationships with a pharmacist, felt that they were well supported in their medication management role; whereas those with poor or even no relationship with a pharmacist felt that they had limited access to information and support. This was similarly reported by caregivers in While et al's. (2012) study, who valued personalised service from their community pharmacist. Given that community pharmacists are viewed by caregivers as an important source of medication management support and information, it is important that pharmacy stores are structured to provide ready and easy access to pharmacists and not just sales assistance.

Finally, another source of medication management information and support for the majority of spouse caregivers in this current study was their participation in a carer support group, especially ones which were specific to their own ethnic minority backgrounds. These groups which are often facilitated by multicultural workers provide a time for family caregivers to gain some respite, share advice and ask questions (Hornillos & Crespo 2011; Ivey et al. 2012). Such groups could provide a good place for distributing caregiver medication management information and/or provide both verbal and written information in their own translated languages.

Limitations

Several limitations need to be acknowledged in this current study. The small non probability sample limits the generalizability of the study results although it is characteristic of similar qualitative studies of family caregivers of people with dementia (Kaasalainen et al 2011; While et al. 2012). Despite the small sample size however, there was a consistency of findings across focus groups and individual semi-structured interviews with significant key findings relevant to the research question identified. Whilst we do not claim to have reached a point of certainty with regard to data saturation, we are confident that the key issues identified may be applicable to family caregivers in other contexts and warrant further investigation.

Implications for practice

In an attempt to minimise stress and conflict between the family caregiver and the care recipient, regular medication reviews for the care recipient should be encouraged. These medication reviews should be carried out with the aim of simplifying the medication regime

of the person with dementia. During the review, strategies could be suggested which could be used to encourage the care recipient to take their medications safely and effectively.

It is important for all health care professionals to provide medication management information to family care givers, especially for those from ethnic minority backgrounds. In addition to providing information and resources written in simple, easy to read English, health professionals need to be mindful of recommending other available resources, such as internet sites, CDs and DVDs, some of which may also be available in different languages. .

Health professionals need to ensure that they develop good relationships and partnerships, with family caregivers, especially as the cognitive abilities of the person living with dementia declines. To assist with developing these relationships, health care professionals need to ensure that they use interpreter services when appropriate, in providing advice and information to caregivers and care recipients with limited English proficiency skills.

In addition to seeking advice from their health care professionals, family care givers of people living with dementia, should be encouraged to look after themselves and to attend dementia specific support groups, which maybe be available in their own ethnic minority backgrounds.

The findings of this study suggest that further research that investigates wider ethnic minority family caregiver medication management roles beyond discussions of compliance and adherence are warranted.

Conclusion

Medication management is a daily task for many community-dwelling people living with chronic disease, such as dementia. As many of these people living with dementia experience

progressive cognitive decline, the control of the medication management role will become that of their family caregivers. Unfortunately, during the transition phase the medication management role can be quite problematic for the family caregiver and can often be associated with both stress and conflict. One of the best ways in which to help combat this stress and conflict is to ensure that all family caregivers are provided with good quality, timely information and resources from reputable sources which include healthcare professionals, support groups and trustworthy internet sources. Consideration needs to be given to improve the usefulness of provided information, ensuring that it is presented in easy to understand English and translated into community languages, as well as being made available in other formats, such as visual presentations.

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