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ORIGINAL ARTICLE

Culturally and Linguistically Diverse (CALD) Families Dealing with Dementia: An Examination of the Experiences and Perceptions of Multicultural Community Link Workers

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Abstract Dementia is a chronic illness involving increasing levels of care, often provided by family members, particularly in culturally and linguistically diverse (CALD) communities. Multicultural community link workers are often the primary service providers assisting families to access health and welfare services and as such have extensive experience of, and possess in-depth knowledge about, CALD family care-giving for dementia. While research has been undertaken on dementia in CALD communities, this research has not focused on the experiences and perceptions of these multicultural workers with regards to CALD family care-giving. In response to this gap in the research, this paper presents the results of an empirical investigation of multicultural workers' perspectives with regard to the cultural traditions informing CALD family care-giving, CALD families'

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understandings of the term ‘carer’ and family arrangements regarding care. Due to their close relationship and knowledge of families, multicultural workers can offer an important perspective that is invaluable in informing the provision of carer education and support within CALD communities.

Keywords CALD · Care-giving · Dementia · Families · Multicultural community link workers · Ethnic minority

Introduction

Dementia incidence rates are increasing rapidly, with international projections of 63 million people having dementia by 2030 (Access Economics 2006a). Caring for a relative with dementia can take both a physical and emotional toll on family members (Dahlberg *et al*. 2007; Samuelson *et al*. 2001).

Research examining dementia care among non-Anglo populations in English-speaking countries has only emerged in the last 30 years (Farran *et al*. 2003). The vast majority of work on this topic has been conducted in North America (Gallagher-Thompson 2006; Janevic and Connell 2001) and has focused predominantly upon Asian (Liu *et al*. 2008; Wang *et al*. 2006), Hispanic/Latino (Montoro-Rodriguez *et al*. 2006; Neary and Mahoney 2005) and African American (Hinton *et al*. 2005; Vickrey *et al*. 2007) populations. Within an Australian context, there has been limited research focusing on dementia within CALD communities.

The conceptual framework underlying this study is the examination of cultural influence on the experience of dementia caregiving. Previous research has illuminated some of the problems faced by families and communities who may not interpret dementia as a disease (Hinton *et al*. 2005) and who may experience difficulty accessing health services for a range of reasons, including cost of care and uncertain immigration status resulting in unwillingness to complain about health services (Neary and Mahoney 2005). Studies also reveal various interpretations of dementia across different cultures and acknowledge the importance of considering such variations when diagnosing dementia. One ethnographic study revealed that clinicians who consider religion and culture when making a diagnosis of dementia can develop a different interpretation of symptoms they might otherwise consider to be symptomatic of dementia (Elliot and Di Minno 2006).

A key aspect of caregiving that is seen in many cultures is the central role of the family. Filial piety, meaning children should care for their elderly parents (McBride *et al*. 1996) is a central concept in Chinese culture and this provides strong motivation to providing care within the family, as opposed to using formal services (Dilworth-Anderson and Gibson 2002; Wang *et al*. 2006). The Spanish concept of *familismo* means that the needs of the family are prioritized over the needs of individuals within the family (Villa *et al*. 1993) and this influences families’ decisions about providing (Montoro-Rodriguez *et al*. 2006; Neary and Mahoney 2005). Other studies have identified the role that acculturation and inter-generational relationships play in Chinese and Spanish-speaking families’ decisions about caregiving, particularly in regard to residential care (Wang *et al*. 2006; Mahoney *et al*. 2005).

The research reported in this paper also focuses on multicultural or culturally and linguistically diverse (CALD) populations – the term used in Australia since 1996 to describe communities other than the majority Anglo community (Sawrikar and Katz 2008). Australia is a highly multicultural country. Out of a total population of around 22,701,500, the percentage of people born overseas was 27% as at mid-2010 and these people were born in over 200 countries (ABS 2011a). Like many other countries, Australia’s population is ageing significantly. The proportion of people over 65 years is expected to increase from 13% in 2007 to around 24% by 2056. This trend is the result of sustained low fertility, combined with increasing life expectancy (ABS 2011b). These two demographic factors suggest there will be an increase in the prevalence of dementia within CALD communities.

Successive governments have trialled and implemented a number of different models in providing health services to CALD populations including introducing ethno-specific services staffed by bilingual workers as well as ethnic health workers employed within the public health system (Garrett and Lin 1990; Matthews *et al*. 2008). A third means of service provision has involved utilising the skills of bilingual staff not working in a designated bilingual position (Garrett and Lin 1990). Since the early 1990s, further initiatives have been implemented to address the needs of older CALD communities. Two Commonwealth Government-funded programs are the Community Partners Program and the Partners in Culturally Appropriate Care which have aimed to increase access to mainstream aged care services amongst CALD communities (Department of Health and Ageing 2009).

The study presented here draws upon interviews with multicultural community link workers employed in the various programs outlined above with a focus upon workers' perspectives on the dynamics and management of family care-giving for dementia in CALD communities. To simplify reporting from here on, we refer to all workers interviewed as multicultural workers (MW). Multicultural workers typically provide health education and promotion, community development, information and support groups and, to a more limited extent, casework. The persons occupying MW positions may come from a range of professional and work backgrounds, but essential requirements for these positions include proficiency in the relevant community language, an understanding of the cultural norms of the community, a sound knowledge of the principles of access and equity, an understanding of the Australian healthcare system, and the ability to work effectively with their communities.

Multicultural workers hold a unique standing in relation to CALD communities – their position as workers means they retain some professional impartiality whilst remaining very close to families. Reports, small studies and position papers (e.g. Cultural and Indigenous Research Centre Australia 2008; Kratiuk *et al.* 1992) have included the views of multicultural workers about pertinent issues that CALD carers face, including carers' difficulties in understanding and accessing Western health systems, coping with dementia-related stigma, gaps in services and family arrangements regarding dementia care-giving. Building upon this earlier research, this study has set out to provide a rigorous, in-depth empirical account of multicultural workers' experiences and perceptions regarding the influences on, and patterns of, family care-giving for dementia in CALD communities. It is essential – in light of the rapidly increasing number of CALD people living with dementia (PLWD) (Access Economics 2006b) – that insights from the experiences and perceptions of multicultural workers be examined and understood as one means of helping inform and guide practitioners, policy makers and clients of CALD dementia care and services.

Methods

Ethics and recruitment

Ethics approval was obtained from the University of Queensland (Approval number 2008001934) and the Sydney South Western Area Health Service Western Zone (Approval number HREC/09/LPOOL/50) Human Research Ethics Committees.

Participants were recruited through local established networks and by snowballing technique. The project followed a purposive sampling frame whereby the sample choice was guided by the aim and objectives of the project and attempts were made to recruit a cross section of participants, at least five from each language and a diversity of role types. To assist in this, a spreadsheet of multicultural workers in the local area was draw up and the author DB systematically approached each of them about the project. This strategy worked well, particularly as workers that DB encountered initially referred her to other multicultural workers.

Participants

Four Australian CALD communities – Arabic, Chinese, Italian and Spanish-speaking – were the focus of the research. These communities were chosen as they included some of the larger groups in the local area and are distinct from each other in terms of language, migration history and acculturation. Twenty-four MWs participated in the study and their backgrounds are represented in Table 1 below.

Prospective participants were provided an information sheet outlining the aims of the study, the focus of the questions to be asked in the interview and how data would be used. Participants were given an opportunity to ask questions and signed consent forms prior to commencement of the interviews.

Data collection and analysis

Interview questions were generated through separate reviews of local/regional and academic literature alongside consultation with each of the four Peak organisations providing services and support for the CALD communities under study. Additional questions and question design was undertaken via an iterative process during fieldwork (i.e. in response to important issues raised by the informants themselves during interview). All the interviews were conducted by DB and ranged from between half an hour to 2 h and 15 min in duration. All interviews were conducted in English as all the multicultural workers interviewed were fluent in the English language. Field notes, including descriptions of participants, settings, reflections on the interview process and the interview itself, along with more analytical notes that included comparisons between participants (Halse 2002) were completed after each interview. Interviews were digitally recorded and

Table 1 Characteristics of study sample of multicultural workers

Language background	Arabic	Chinese	Italian	Spanish
	6	7	4	7
Type of organisation	Health service	Mainstream community	Multicultural community	Ethno-specific
	3	5	2	14
Type of position	Dementia specific	Aged care	Mental health	Generalist position
	6	9	1	8
Gender	Male	Female		
	2	22		
Primary work role	Service coordinator	Direct care worker	Community development	Group worker
	3	10	4	7

later transcribed verbatim. Culturally appropriate pseudonyms were used (Jefferies 2006) in place of participants' names and all other identifying details removed.

QSR NVivo was used to organise the data and assist in the coding process. A modified version of the framework approach developed by Pope *et al.* (2000) was used in data analysis. Firstly, the transcripts and field notes were read several times. A thematic analysis was then conducted, where answers to the interview questions along with other themes that emerged at this level were coded. Finally, a strategy of mapping and interpretation was undertaken whereby data was examined in the context of the research questions and associations between themes identified, as were negative cases, meaning data that contradicts central themes (Pope *et al.* 2000, p.114). Initial coding was undertaken by DB and researcher triangulation employed via code and interpretation cross-checking by two other members of the research team (JA and CS).

Results

The analysis examined MW's experiences and perceptions regarding the influences on and patterns of family care-giving for dementia in CALD communities. Three main themes were identified: cultural and familial norms pertaining to illness and older people; understanding and naming the term 'carer'; and patterns in family care-giving. These three themes and a number of sub-themes are discussed in more detail below.

Cultural and familial norms pertaining to illness and older people

Participants explained how from their experience, specific cultural traditions – what CALD families of persons living with dementia deemed acceptable and reasonable roles for family members – were evident. The multicultural workers identified a number of family expectations that come into play when an elderly person is unwell. While most of these issues were specific to dementia some were more broadly relevant.

Keeping dementia in the family

Participants from each of the four language groups outlined an expectation amongst CALD communities and families that elderly people would be cared for by one or more family members – either while remaining in their own home or staying in the home of the family carer. In a sign of solidarity and support for such traditions, some participants made reference to their own families and personal experiences in explaining the importance and pride of caring for an elderly relative

> but if anything happens to anyone of them, lets say, God forbid one dies, definitely, definitely I will insist that Dad or Mum stay with me, although they are still independent, unless they do not wish to do that (.) but I would (.) I wouldn't think of nursing home (Chione, Arabic MW)

Interviewees described how CALD families often strive to maintain the elderly person at home even when caregivers faced their own health problems. A separate but interconnected issue raised was how caregivers are often reluctant to disclose or acknowledge dementia in their elderly relative to anyone outside the family unit. While this was a reluctance outlined by multicultural workers from all four cultures under study, there were nevertheless some variations within this larger theme. Both Arabic and Spanish workers suggested people would discuss the condition with their GPs, and Arabic workers suggested this tended to be a bi-lingual GP. Chinese workers explained how their clients discuss the issue with close friends and one of these workers suggested elderly Chinese discuss dementia with their friends before their children. Analysis of our data suggests that of all the four communities, Italians were the most reluctant to discuss dementia outside the family. Italian multicultural workers attributed such reluctance to a fear by the family of how the person living with dementia and their broader family would be perceived by other community members.

Judged by the community

Families' fears of being judged by other members of the community was a prevalent issue outlined in the interviews with Spanish and Italian participants. They noted that it was commonplace for members of the community to talk about other individuals and families in regard to their behaviour and in this instance, their actions regarding dementia care-giving

> Whatever happens to them in life and then everyone is going to have the right to point at you…Italians are exactly the same as we are, the covert pressure; the pressure that's put onto you is so strong (Isi, Spanish MW)

Participants suggested that community discussions about another family or individual ranged in terms of content, such as whether they wore the appropriate clothes for a funeral through to opinions about families' decisions to place a relative in residential care. The multicultural workers explained that the reactions of others in the community informed the decisions of CALD families due to the shame and embarrassment associated with negative community reactions. Community shame likely contributes to why families keep matters such as dementia private

> in front of the relatives and friends there seems to be a lot of cover ups (Kamalia, Italian MW)

Women as carers

Although the Spanish respondents did not raise this issue, the other participants indicated that women commonly have responsibility for the main domestic duties within their CALD community, irrespective of whether these women were the wife, daughter or daughter-in-law of the person living with dementia. As such, these participants explained, it therefore followed that the daily duties of caring for an elderly person would also be the responsibility of a female family member

> In middle-eastern communities it's always the daughter in law…she is the one I speak to…who is the real carer (Chione, Arabic MW)

Women were perceived by some participants as having to juggle a multitude of roles and tasks along with responsibilities such as paid work, childcare and household chores. The cultural expectations of these women, namely what is deemed as their appropriate behaviour and roles, were seen as exacerbating the many difficulties these women experience, at both the family and broader community level.

Understanding and naming the term 'carer'

Multicultural workers claimed that the majority of families for whom they provided services perceived caring as a normal and acceptable part of being a spouse or child in their respective culture and that family members often failed to recognise that caring could be a new, specific role beyond normal family responsibilities. These circumstances were perceived by the particpants to have a number of significant consequences for families and carers, including a tendency for carers to be overburdened and stressed as well as developing their own health problems. In some cases, it was explained, the carer was in worse physical health than the person with dementia. Another consequence of families' reluctance to demarcate caring to a special status beyond familial responsibilities was that carers did not take the assistance they were entitled to, particularly government financial support for carers such as the Carer Allowance and Carer Payment. Participants described how families often could not relate to the concept of receiving payment for caring for their family member.

Informants outlined what they perceived as the underutilisation of ethno-specific services due to a lack of familiarity with the term 'carer'

> The concept is very hard to get across, not only for the Chinese but for other ethnic communities also, that they don't identify themselves as carers, that's why aha when we run the carers support group it is difficult to get anyone to come (Jacqui, Chinese MW)

Use of services was one of two ways that participants suggested families became knowledgeable about the term 'carer'. The other means of awareness was in response to the high demands the person with dementia placed on families. One interviewee suggested adult children were more likely than other older family members to use the term 'carer' as they would have greater access to information as well as having to leave their own homes to provide care

> I think with the children because of the different generation and the exposure to the information, they probably would refer to themselves as carers more so than the parents, because they are often removed from the home, so they are coming in (Delia, Italian MW)

The multicultural workers described how they provided a considerable amount of education to carers and suggested that very few families would view or label themselves as carers without prompting or education. The workers explained how they attempt to alert family members to an explicit, formal carer role in a number of ways, such as by explaining that the physical work carers do is outside the norm for an adult family member. One Spanish worker suggested families' recent willingness to accept the term 'carer' was that there was now acknowledgment of the term in their country of origin. However a few of the Chinese workers suggested the term 'carer' was particular to Australia

> we always give them a title, this is your title, as a carer…once they become a carer they feel like "oh, ok" I'm doing good…I become useful for the Australian government, and this contribute a caring role, rather than, you know, sending Mum or Dad to home and use lots of tax payers money (Rachel, Chinese MW)

As Rachel implies in the quotation above, this formalising of the caring role was seen by the multicultural worker as serving to reinforce families' pride in caring. Multicultural workers suggested that a family's use of the label 'carer' to define their role tended to encourage a willingness to use services, obtain the carers pension and practice self-care.

Patterns in family care-giving

Three care-giving scenarios were identified from the interviews: children as main carers, spouse as main carer and family sharing care.

Children carers

Interviewees identified much variation amongst (adult) children carers, as opposed to spousal carers. More personal factors that impacted on the decision-making of children in relation to their parents' care included the relationship between the parent and children prior to dementia developing and the parents' views about how they wanted to be cared for, which were sometimes communicated directly or indirectly to their children. One Italian participant mentioned that the gender of the person living with dementia and the child mattered when it came to providing care, as parents would not accept personal care from a child of a different gender.

One overall theme across the interviews was that generation or age had less of an impact on the decisions children carers made about dementia, while acculturation was seen to have a more significant effect. For instance, participants identified children in their early twenties who took a very traditional approach to caring for the elderly and would readily step into this role

> very, very young and they feel it's my duty, my responsibility to look after mum (Luciana, Spanish MW)

Participants suggested that children were generally more knowledgeable about dementia due to their education and ability to use technology but, that for some children, better understanding did not translate into willingness to provide care.

> they're not willing to work around or they're not willing to say "we might move Mum and Dad up closer, or we might need to move back or something, you know, we do hear a lot of that, um (.) it's like "what; what can you people do to help? (Salvagia, Italian MW)

Participants suggested that both education and acculturation were reasons why children placed their parents in nursing homes. Education was seen as having a positive impact on CALD families, suggesting that children who had received more education were more informed about services and tended to be less stressed as caregivers, as they would utilise services to assist in caring for the person with dementia. Multicultural workers mentioned that families struggled in trying to reconcile multiple values and commitments, such as financial considerations with family and cultural expectations. They indicated that work and mortgage commitments sometimes informed people's decisions to use services, but that nursing homes were only an option once other alternatives had been tried and it was clear that the person with dementia needed a higher level of care.

Other issues mentioned in the interviews as specific to children carers included disagreement between siblings and conflict with the carer's spouse regarding care-giving commitments. Interviewees explained that the decision to place their parents in a nursing home was often a major issue of contention between siblings. They described how having different commitments and/or values resulted in disagreement between siblings, a situation that was compounded, as Kelly, a Chinese MW explained, when siblings were living in different countries

> How can I tell the people in Hong Kong that my mum got dementia here? Then how dare you send your Mum to a nursing home? How can you tell that to my brother? You can't (Kelly, Chinese MW)

Kelly went on to explain how the situation could lead to great distress for the child carer who may hold a contrasting viewpoint to those of siblings regarding the preferred approach to caring for the person with dementia. In addition, the carer may be somewhat hesitant about or unfamiliar with services anyway, because of recent migration or holding some more traditional beliefs (e.g. elderly should be cared for by family). In these circumstances a lack of family support, or straightforward criticism, was perceived by the multicultural worker as often isolating the carer – with consequences for both their own feelings of self-worth and dealings with services and service providers.

The other source of sibling conflict identified was a situation where one sibling provided the majority of care and received limited support from the rest of the family. In some cases, participants suggested, the carer was caught in a bind, as when the carer complained about being the only one providing care, the siblings' suggestion was to place the person with dementia in a nursing home, which was not a satisfactory suggestion for the main carer.

Participants discussed how caring responsibilities resulted in problems between spouses. This conflict generally occurred when it was the carer's parent who had dementia, but one participant mentioned how daughters-in-law find it acceptable to provide care to the person with dementia but struggle when the person has high needs. This situation results in disagreement between husband and wife. A more common scenario was when one spouse, usually the husband, objected to their wife caring for their parent and even refused to let her be involved

> The husband he said "Well you have to make a decision…You don't love your family enough because you look after your mother. You provide more care for your mother" (Luciana, Spanish MW)

Spousal carers

Participants identified particular issues pertaining to spousal carers. Spouses were seen to have different reasons for providing care, one of which was explained as pressure from their children, a theme particularly prevalent in the interviews with Spanish MWs

> A wife who was taking care of her husband suffering from dementia told me "my children oppose to send their father to a nursing [home] even though they see it is getting very hard for me" (Alandra, Spanish MW)

The physical burden that spousal carers experienced was discussed by many of the participants. Both male and female spouses were seen to struggle with maintaining surveillance of, watching and physically moving the person with dementia. However, participants explained that such circumstances did not often lead to requests for help or support from services until a crisis occurred. This was perceived by the multicultural workers as another difference between spouse and child carers. Spouses were seen as more likely to attempt to manage the situation themselves and/or to seek assistance from their children prior to calling on the support of formal services.

> If it's a husband or wife, it's different. I find that they will (.) do what they can to help and won't ask for something unless they are in dire straits (Franzea, Spanish MW)

When they finally did receive services, participants indicated that spouses were very grateful for any help they received, whether it was practical assistance or emotional support

> The old (aha) generation (aha) say, "no, its my responsibility to take care. But the old generation, like me (aha) very worried (aha) something about they take care properly of the consumer (Gabriela, Spanish MW)

Family sharing care

The third care-giving model mentioned was involvement of the entire family in caring for the person with dementia. In this instance, families organised themselves so that members of the family could meet their other commitments, such as work and care of their children, and no one person became exhausted. This model was discussed by a number of Spanish and Arabic participants. Arabic multicultural workers linked this dynamic to culture. Chinese and Italian workers did not explicitly mention shared care, although they indicated it did occur and one Chinese participant explained that they suggested such a model to families when seeing the primary carer becoming tired and/or emotionally drained. Multicultural workers suggested that sharing care was the most appropriate and sustainable option for all people concerned

> I had a family where the father migrated from Spain um, he started having behavioural problem, they were all born here so they did understand the concept of everything, they could understand, but the pressure of the family made them organise themselves in such a great way, that they maintained their father at home…they took shifts, who looked after the father, the four kids (Isi, Spanish MW)

Despite acknowledgement of shared care as being the best approach, participants noted that different family members had varying views about providing care. Although mentioned by only a few interviewees, it was suggested that diverging approaches to care may result in both the person with dementia and the primary carer, missing out on services

> With the younger generation they do seek out services, but then it becomes the obstacle of getting the person with dementia, or the carer, to accept those services, and that I think, is the hardest thing for the children as carers to overcome…I think they are [children carers] more in tune with what their needs are as carers but it doesn't, progress (.) um, to the person with dementia to allow them to have what they need (Delia, Italian MW)

Discussion

This study makes a significant contribution to the literature by highlighting the perspectives of multicultural workers on family care-giving of people with dementia from within CALD communities. Multicultural workers are part of their own communities, and because of this have a very close relationship to the families with which they work. They can draw from a diversity of family experiences, including different degrees of acculturation, they understand their culture and how culture may inform care-giving. Thus multicultural workers provide a unique perspective regarding CALD family care-giving.

The central finding of this study is that multicultural workers perceive and experience many different influences on decisions made about family care-giving. These include cultural expectations about what is seen as appropriate behaviour for individuals and families, as well as the relationship carers have with the person living with dementia, which was sometimes perceived as linked to culture and practical considerations like financial commitments. It is evident from the multicultural workers' perspective that the views of many family members (including those who were living in another country) are central to decisions about care. Previous research has not focused on the roles of multiple family members in the provision of care, despite cautions that this model needs consideration in discussing CALD communities (Janevic and Connell 2001). The current study illustrates that in some families, many people are involved in the provision of care. Furthermore, despite potential disagreements between different family members involved, the multicultural workers present such a shared approach to care as their preferred model due to the decreased burden upon individual family members.

Another important point as reported by participants was that few CALD families understand the term ‘carer’ or the implications of the term. This is an extremely important finding, considering the complex emotions and burdens many carers experience along with reports that CALD carers are reluctant to use services (Rao *et al*. 2006).

These findings have implications for carer education and support. With regard to education, it is evident that CALD care-givers do not share the same meanings and interpretation of health and welfare terminology (i.e. carer) as those from Anglo populations. It is therefore important that staff provide education, check and confirm people’s understandings and explain terms and issues in a way that makes sense to the individual. Currently, people may not use services due to a lack of awareness that services targeting carers are intended for families of people living with dementia. Support programs for carers should also include strategies to manage competing values in decision-making and dealing with family disagreements in the context of dementia. As other researchers have suggested, it is important that health service providers be sensitive to different family structures and be prepared for conflict when several or many family members are involved in decisions (Gallagher-Thompson 2006) – as people may hold different cultural values (Ho *et al*. 2003) which will impact on decisions made about care-giving. It is important that the multiple demands facing CALD carers be given due consideration by all clinicians and educators involved with families in dementia care.

While this study has provided useful insights to the experience of family care-giving within CALD communities, there are limitations to this type of exploratory study. The qualitative design means that the findings cannot be generalised to other CALD communities. Another limitation is that this paper has only presented the views of one group of stakeholders – multicultural workers. To gain a more complete understanding of the issues it is necessary to include the views of other stakeholders, particularly family carers themselves.

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