American Journal of Alzheimer's
Disease & Other Dementias®
26(4) 290-297

DOI: 10.1177/1533317511411908
http://aja.sagepub.com
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Experiences and Perceptions of Culturally and Linguistically Diverse Family Carers of People With Dementia

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Abstract

Dementia incidence rates are rapidly increasing among culturally and linguistically diverse (CALD) Australians, and there is very little local research to inform practice. In response, a qualitative study employing focus group methods was undertaken with carers from 4 CALD communities—Arabic-speaking, Chinese-speaking, Italian-speaking and, Spanish-speaking. The study examined the experiences and perceptions of these family carers with regard to their caregiving for a person living with dementia (PLWD). Analysis revealed that while considerable similarities exist across the experiences and perceptions of carers from all 4 CALD communities, there were nevertheless some important distinctions across the different groups. These study findings have significant implications for those working with CALD communities.

Keywords

dementia, family carers, culturally and linguistically diverse, tasks, concerns

Introduction

A Focus Upon Anglo-Australian Carers in Past Literature

People living with dementia are frequently cared for by family members.[1] The physical, psychological, financial, and relational impact of family caregiving for dementia has been explored in many studies.[2,3] Nevertheless, the majority of caregiving research in Australia has focused on Anglo-Australian families. This research suggests that carers experience significant levels of stress, partly due to difficulties communicating with health professionals and accessing support services.[4,5] Although Anglo-Australian carers are involved in visits and care planning with doctors,[4] they have also been found to be concerned about their ability to cope with caregiving, the behavioral and personality changes of the person living with dementia (PLWD), and the necessary modifications to their own daily routines in order to accommodate the PLWD.[6]

Culturally and Linguistically Diverse Communities and Caregiving: Drawing Upon North American Literature

The predominant focus upon majority culture in caregiving literature in Australia is to some extent also reflected in other Western countries such as the United Kingdom and United States.[7] Nevertheless, cultural diversity has more recently emerged as a focus of dementia caregiving research especially in North America with work examining African American, Chinese, and Hispanic/Latino communities.[8] Research with African American carers reveals that the respect accorded to elders often means families provide care and numerous relatives are involved in caregiving.[9] Other findings from this study suggest African Americans have negative experiences with formal health services and use religion as a source of support.[9,10] Research rebutting these findings claims that the experiences African American carers cannot be isolated from other structural and financial difficulties in their lives.[11] While African American carers struggle to access services, after gaining access, they report positive experiences with service providers.[11]

Past literature has identified important aspects of Chinese-speaking families which impact upon family caregiving for the PLWD. One is the stigma associated with dementia,[12] and another is the centrality of filial piety, whereby children have a duty to care for their elderly parents.[13] As a result of these 2 features, Chinese-speaking families have been found to more

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often provide home-based care for relatives, as opposed to using formal services.[14,15] The concept of familism (*familismo* in Spanish), referring to a prioritization of family needs over individual needs,[16] has been identified in research with Hispanic/Latino carers. Familism is seen as informing the decision of many Spanish-speaking families to provide home-based care.[17,18]

Studies have also identified acculturation as impacting upon the decision making of Chinese-speaking and Spanish-speaking families about caregiving, particularly with regard to residential care.[9,15] In 1 study, adult children carers expressed concern that the next generation may not provide the same level of care when needed as previously provided to the elderly individuals in their culture.[19]

Although some US research may be applicable to the Australian context, there are differences between the systems and the communities in the 2 countries and caution should be employed in making comparisons (Barker, 2010, personal communication). For example, aside from the fact that Australia has a public health service (albeit not comprehensive) whereas US healthcare is largely unavailable without private insurance, the close proximity between the United States and the country of origin of US-based Spanish speakers may make it easier to provide family-based care in the United States, irrespective of cultural values. Furthermore, Spanish is the second language in the United States, which has a large Spanish-speaking community,[20] whereas the number of Spanish speakers in Australia is significantly smaller.

Selected Culturally and Linguistically Diverse communities in Australia: A Brief Context

The study presented here examines the experiences and perceptions of family carers from 4 culturally and linguistically diverse (CALD) communities—Arabic-speaking, Chinese-speaking, Italian-speaking, and Spanish-speaking.

Arabic migration to Australia began in 1903 and Arab migrants were predominately Lebanese until the 1960s. The Lebanese remain the largest group of Arabic-speaking migrants in Australia, but people have also more recently come from Egypt, Iraq, Jordan, Palestine, and the Arab Peninsula.[21] There have been multiple waves of Chinese migration to Australia.[22] A significant number of Chinese migrants arrived in the 1970s and 1980s and many sponsored family members after obtaining residency.[23] Italians are 1 of the oldest CALD communities in Australia. Italian migration began in the 1800s and large numbers came between World War I and II.[23] Spanish-speaking people in Australia come from a range of countries, with large numbers from Chile, Argentina, and Uruguay.[24] There are differences in the migration circumstances of various Spanish speakers. In the 1960s, Spaniards came under a skilled worker scheme, while in the 1970s Spanish speakers were mostly from South America and often escaping military regimes.[23,25]

Australian investigations into family caregiving practices suggest that older Chinese, Italian, and Arabic people expect their children to care for them and that the Arabic and Italian elderly individuals often believe they will die at home.[26] Australian Spanish-speaking communities also place importance on family-based care, although some people are aware that this is difficult for children juggling other commitments.[23]

Given the paucity of Australian research examining family caregiving within CALD communities,[27] the potential difficulties of drawing upon international literature and the rapid ageing of CALD populations in Australia,[28] there is a pressing need to provide a local evidence base to inform practice in this area.[27] The aim of this study is to provide the first examination of the experiences and perceptions of family carers of the PLWD from 4 Australian CALD communities. This investigation provides a basis for understanding the roles and needs of family carers for a PLWD across and between individual CALD communities.

Methods

Design

This article is part of a larger qualitative study examining family caregiving for dementia in CALD communities in Australia. Following a modified grounded theory approach, the study employed focus group methods and in-depth interviews to examine the experiences and perceptions of a number of stakeholders regarding CALD family caregiving. Interviews were conducted with multicultural workers, bilingual general practitioners, and geriatricians while family carers participated in focus group discussions. This article focuses specifically upon the experiences and perceptions of the CALD family carers and draws exclusively upon the focus group data collection with these participants.

The project received ethics approval from the University of Queensland Human Research Ethics Committee and the Sydney South Western Area Health Service (Western Zone) Human Research Ethics Committee.

Focus groups were considered an appropriate methodology for this investigation, given that they provide an opportunity for a group discussion of a topic and highlight contrasting and shared views among group participants.[29] Moreover, focus groups, like qualitative methods more generally, are also considered well suited to exploring topics about which little is known—the experiences and perceptions of CALD family carers for the PLWD being 1 such topic.

Sample

The selection of the 4 language communities for examination in this study—Arabic-speakers, Chinese-speakers, Italian-speakers, and Spanish-speakers—was based upon their being the most prevalent CALD groups in the local area and their distinction from each other in terms of language, migration history, and acculturation. Acknowledging the diversity among these language communities, participants were recruited on the basis of language spoken.

Family carers were included in the study if they had an immediate or extended family member with dementia who they cared for within the last 12 months (for 1 month or more). The

PLWD had to meet 2 criteria: to be diagnosed with dementia and speak (or prefer to speak) a language other than English at home. There was no differentiation between the types of dementia. No information was collected on the PLWD, participants simply indicated whether the PLWD met the above criteria. More than 1 member of a family was allowed to participate in focus groups and all language communities had groups with more than 1 family member present. Participants were excluded if they or their family member who was a PLWD did not meet the relevant criteria discussed above.

A total of 16 focus groups were conducted (4 per community). A total of 121 family carers (19 Arabic, 37 Chinese, 40 Italian, and 25 Spanish speaking) participated in the focus groups, with an average of 8 participants per group. Data collection was terminated in line with thematic saturation—the point at which no new significant issues arise from subsequent fieldwork. The youngest carer was 17 years and the oldest was 90 years; 88 were female and 33 were men. In all, 25 were spouses, 93 were adult children (or the spouse of the PLWD adult child), and 3 grandchildren of the PLWD.

Procedures

Bilingual fieldworkers were central to the study. One fieldworker per community was employed. The fieldworkers were responsible for recruitment and facilitation (moderation) of focus groups. In addition, fieldworkers also promoted the project (both verbally and in writing) to community organizations and groups, ethno-specific health/welfare services, and places of worship. Each fieldworker, in close consultation with the research team, was responsible for developing recruitment flyers and study announcements in the community language. Fieldworkers also consulted with interpreting staff to ensure the accuracy of translations and word choice.

In selecting the fieldworkers, priority was placed on choosing individuals who were involved with their communities in a health, welfare, or educative role and, if at all possible, had research experience. The fieldworkers all had undergraduate degrees in social science or related areas and were trained by experienced members of the research team in duties and skills necessary to facilitate the focus groups. In addition, a member of the research team was also present (with an interpreter) at all focus groups. This provided an opportunity to maintain ongoing training and support and ensure the quality of the fieldworkers' tasks throughout the research process.

A set number of questions were provided to loosely help guide the focus group discussions. However, it was emphasized to fieldworkers that discussions should be predominantly inductive and flexible, as consistent with a grounded theory approach. The initial questions focused upon a number of areas/issues including community understandings of dementia and dementia-related information; pathways to obtaining a diagnosis; aged care services, and support for family carers. Each fieldworker translated the questions for their community.

Following approvals from the relevant ethics committees, the written information about the study and consent forms were professionally translated into each of the 4 languages by the Health Language Services (Translation Service). The Health Language service employs people accredited by the Australian National Accreditation Authority for Translators and Interpreters (NAATI).[30] In translating a document, an accredited translator translates the text and then forwards the translation and the English version to another accredited translator to check for omissions or mistranslations (Health Language Service, 2011, personal communication). Documentation associated with the research was provided in both English and the appropriate community language.

As well as the bilingual fieldworkers, 4 NAATI accredited translators were also employed on the research project and attended the focus groups. Their role was to produce, in English, a transcript of the focus group discussion for data analysis. The reason data were analyzed in English was one of the necessities, as only 1 researcher was bilingual in 1 community language. Steps were taken to ensure concepts were not lost in translation such as interpreting staff adding notations to help explain the significance of cultural idioms.

All focus group participants were provided with taxi vouchers for their travel to and from the focus group sessions. Department store vouchers ($50) were also provided as an incentive for participation. Fieldworkers explained the study and consent process to all participants prior to conducting the focus group and including explanation of the aims of the research, how information and data were stored and later used. All participants signed consent forms, either in their own language or in English. The focus group discussions were conducted mainly in the community languages, digitally recorded, and lasted between 1 to 2 hours and 3/4 hours in duration.

Data Analysis

All fieldwork digital recordings were transcribed to word file and thematic analyses were undertaken without the aid of a qualitative analysis computer package. The thematic analysis followed some core tenets of the framework approach as developed by Pope et al[31] such as familiarization, indexing, charting, and mapping/interpreting the data. Themes were initially developed by 1 researcher and checked by 2 other members of the research team in line with researcher triangulation. The explanations and merits of any competing interpretations of the data within the research team were then discussed until a consensus was established.

Data were initially analyzed and coded separately for each language group. Data were then combined and broad themes across language groups coded. A number of subthemes within these broad themes were then identified. Transcripts were coded according to themes.

Results

Four themes emerged from the analysis. These are outlined in Table 1 and discussed in more detail below.

Table 1. Findings applicable to specific Cultural Group

Carers Duties

	Physical Care	Emotional Care	Assistance Seeing Doctors	Advocacy in Hospital
Arabic	√	√	√	
Chinese	√	√	√	
Italian	√	√	√	√
Spanish speaking	√	√	√	√

Family-Related Issues

	Gender Matters	Different Levels of Involvement in Families	Family Conflicts
Arabic		√	
Chinese		√	
Italian	√	√	√
Spanish speaking	√	√	√

Emotional and Personal Concerns

	Grief and Loss	No Time for Self	Worry About the Future	Deterioration in Carers' Health
Arabic	√	√	√	√
Chinese	√	√	√	√
Italian	√		√	√
Spanish speaking	√	√	√	√

Dementia-Related Concerns

	Behavior of a PLWD	Confusing Family Members	Safety Issues
Arabic		√	√
Chinese	√		
Italian	√	√	√
Spanish speaking	√	√	√

Carers Roles

Physical care of the PLWD. Family carers from all CALD backgrounds reported assisting their relatives with activities of daily living including bathing, dressing, and eating. In describing the assistance provided to the PLWD, a theme of simultaneous commitment and strain emerged in carers discussions

> We got married when we were 20 years old .... So, I will do everything for her without complaining. I should look after her and serve her .... She is big and fat, I can't lift her up. What I usually do is pull over all of the chairs we have. Then I gently put her onto the shortest chair, and from there, put her onto a higher chair, and then the highest chair to help get her up. My back becomes extremely sore after all that (Chinese family carer, husband)

Many carers performed physical care duties unquestioningly, despite the physical strain it placed on them. The carers described being attentive to the various needs of the PLWD and some mentioned managing aspects of the illness that were outside their knowledge and/or role, including reducing medication or advocating for the PLWD to be on different medications. Both Arabic-speaking and Italian-speaking carers described how they often had to orientate to the PLWD as a child, and Chinese-speaking and Arabic-speaking carers suggested they had a cultural tradition whereby the older person "becomes like a child again." One Chinese carer suggested it would be helpful if more community members also understood dementia in this way rather than in the highly negative terms experienced.

Family members from both genders and with various relationships to the PLWD were involved in the provision of care. Some participants acknowledged the duties they performed as different from cultural and/or gender expectations. A grandchild of a PLWD explained

> He did go to the toilet in the bed and I didn't know what to do the first time, I rang my dad at like 2 in the morning ... and he said ... "well clean it" ... "well, I don't wanna clean it" ... I'm Italian ... my mum still leaves my clothes on the bed in the morning ... how am I supposed to clean an 80 year old man's you know ... I did and then I went outside and spewed my guts out

Emotional support for the PLWD. Family carers explained how attending to the emotional and social needs of the PLWD was as important as responding to their physical needs. A number of the Arabic-speaking and Spanish-speaking carers mentioned constant endeavors to keep the PLWD happy

> I say to her "this dementia is not working well for you" and I kind of make it a joke for her to have a laugh (Spanish-speaking family carer, daughter)

Arabic-speaking carers discussed the need to communicate respectfully to the PLWD and emphasized the importance of not leaving the PLWD alone for their safety and emotional well-being. Arabic-speaking participants suggested that praying for the PLWD, both with them and alone, helped

> when I used to see her repeating a lot without making sense I would grab her hand and pray for her ... she would feel better, emotionally (Arabic family carer, daughter)

Chinese carers explained the importance of treating the PLWD with kindness as this was seen as impacting their overall condition. However, in an attempt to stop the PLWD deteriorating further, several Chinese carers explained how the PLWD needed to be corrected when perceived to be behaving inappropriately.

Assisting the PLWD to visit doctors. Family carers from all 4 CALD communities were involved in assisting the PLWD to visit and consult with doctors, by offering a transport option, interpreting for them, or advocating on their behalf or a combination of all 3.

> I always took Mama to the doctor and I translated, she was happy with what the doctor said (Italian family carer, daughter).

When the doctor did not speak the language of the PLWD, some carers interpreted the discussion between the doctors and the PLWD (and sometimes also for other family members). Family carers also explained how they often followed up after initial medical appointments in terms of arranging subsequent appointments with specialists, completing prescriptions and phoning services as necessary.

Advocating for appropriate treatment in hospitals. Family carers from Italian-speaking and Spanish-speaking backgrounds suggested that hospital staff were often unable or unwilling to accommodate the language and cultural needs of the PLWD

> The problem in hospital is that, as his English is gone, the nurses the doctors do not understand him, then if he needs to go to the toilet there is nobody (Spanish-speaking family carer, wife)

The carers' perceptions of hospitals as unable to cater to the needs of the PLWD often led to carers strategically devoting significant periods of time to supporting the PLWD in the hospital setting. In some cases, hospital staff requested families stay to help translate and understand the patient's needs. In other cases, this request was made by the PLWD who was scared to be left alone in hospital.

Family Issues

Gender Matters in Caregiving

Some of the Italian-speaking and Spanish-speaking carers explained care provision in their families as drawn along gender lines. This was not often questioned and carers did not reflect on the consequences or implications for themselves or others. Female carers defined themselves as responsible for specific tasks such as bathing their mother-in-law which was seen as an inappropriate task for male family members to perform owing to cultural norms. Female carers also noted that female children seemed more willing to assist older family members than sons

> My boys ... they stand back but my daughter, when I left her tonight she was feeding her grandfather (Italian family carer, daughter)

Fitting with this perception, male family carers noted that in doing particular tasks they were transgressing what would normally be expected of them. However, some male carers, mainly spouses, mentioned they were doing new tasks as a result of responding to their partners' dementia

> I've cooked for the last six months, I've never been able to fry an egg, but I've learnt to (Italian family carer, husband)

Different Levels of Involvement in Families

Family carers indicated that, due to various factors, some family members were more involved in the care of the PLWD than others. Sometimes this was due to a preference on behalf of the PLWD. In the Chinese community, such preference was usually for the spouse of the PLWD

> I can only look after him for two or three hours because after that, my father starts to look for my mother. He would ask me where my mother has gone to and say that he wants her back. He is used to my mother (Chinese family carer, son)

It was common, particularly in the Arabic-speaking community, for a number of family members to be providing relatively equal amounts of care for the PLWD. In contrast, while Italian-speaking and Spanish-speaking carers received help from extended family, there tended to be 1 or 2 primary family carers (in the case of a husband and wife). With the exception of the Chinese-speaking participants, carers from all communities explained how having many people involved in caregiving introduced a range of opinions and perspectives and how this could often lead to difficulties when making decisions about care.

Family Conflicts

Indeed, on a broader level, many family carers described how decision making around care for the PLWD sometimes led to family arguments. There were 2 main scenarios outlined by the respondents as causing conflict; the first was that some relatives refused to be involved. In most of these cases adult children family carers resented their siblings not getting involved in their parent's care (attributed by the participants as an inability or refusal to understand dementia and its impact on other family members). In addition, a few Italian spousal carers stated they would like more support from their own children.

> They work, on the weekend do sport. All well, they have different lifestyles (Italian carer, husband).

A second scenario of conflict outlined by adult children carers only related to difficulties between them and their spouse due to the demands involved in caring for the PLWD. Carers explained that sometimes they had to dedicate extensive periods of their time at their parents' home and/or that they were often too exhausted from caring to properly engage with or support their partners at other times. A number of carers explained how their own marriage had suffered and in some cases broken down directly due to what they perceived as the strains and demands of the caregiving role.

Emotional and Personal Concerns

Grief and Loss for the PLWD

Family carers from all communities expressed much grief about the PLWD condition and one specifically challenging issue experienced was the knowledge that despite the time and effort devoted to caregiving, they could not "cure" the PLWD. Carers also struggled with not being recognized by the PLWD, with what they perceived to be the PLWD's loss of dignity and with the ongoing changes as a result of dementia.

Lack of Time for Self

A significant number of Arabic, Chinese, and Italian spouse and children carers described their lack of time to focus on other aspects of their lives, including personal and professional. In recounting their experiences, carers struggled with mixed emotions pertaining to their love for the PLWD, their "role" as family members, their cultural obligations, and the strain they experienced as carers. Some carers noted that even when they were alone the PLWD remained the focus of their thoughts. Several carers claimed methods of relaxation suggested by service providers and friends such as beauty treatments or massage were either too expensive or did not provide any satisfactory stress relief.

Worry About the Future

Study participants from all communities except Arabic-speaking carers expressed concern about the progression of dementia, both in terms of the condition of the PLWD and the level of assistance they as carers would need to provide. Spousal carers worried what would happen if they were to die before the PLWD

> What if she outlives me? Her life will become even more miserable. Yes, she's got our children to look after her, but it's different to the care from a husband (Chinese carer, husband)

Deterioration in the Health of the Carer

Carers from all language communities were concerned about their health and many attributed their health problems to caregiving. Carers' health problems were both physical and mental—some had recently been diagnosed or believed they had depression. A significant number of carers suggested they had become accustomed to coping with multiple problems, like other family issues and financial difficulties, but that dementia was a particularly stressful and constant burden which continued to affect them greatly.

Dementia-Related Concerns

Behavior of the PLWD. Notwithstanding the negative associations with dementia in some CALD communities, Chinese-speaking, Italian-speaking, and Spanish-speaking carers all reported the behaviors of the PLWD as quite antisocial and as having the effect of isolating the PLWD along with other family from wider society. Carers using home care were embarrassed when the PLWD was rude to service providers, including accusations of stealing.

Family carers outlined an ongoing struggle to understand and accept the changed relationship with the PLWD. Carers explained that although prior to the diagnosis the relationship had been close and loving, it was now described as prone to volatility, disruption, and conflict.

Safety issues. Many participants expressed great concern about the safety of the PLWD in their home. Carers of all backgrounds except those who were Chinese speaking recalled troubling incidents where the PLWD had left the stove or tap on or had burned or cut themselves accidentally without realizing. As a result, carers talked of the considerable emotional and physical burden of attempting to provide constant presence and support to the PLWD.

Discussion and Conclusions

The aim of the study was to explore CALD carers' experiences and perceptions regarding caregiving and being a carer for a PLWD. Analysis has revealed that while considerable similarities exist across the experiences and perceptions of carers from all 4 CALD communities, there were nevertheless some important distinctions across the different groups. All communities were heavily involved in the care for the PLWD. However, Arabic-speaking and Chinese-speaking carers did not take an advocacy role in hospitals as described by the Italian-speaking and Spanish-speaking carers. Arabic-speaking and Chinese-speaking carers also reported less conflict with other family members about caregiving decisions than Italian-speaking and Spanish-speaking carers. Gender was not described as impacting care decisions in these latter CALD communities to the extent that it was by the Italian-speaking and Spanish-speaking carers participating in the study. Arabic-speaking carers expressed much emotion and grief about the condition of the PLWD, worry about the future, and the impact of caring on themselves. However, Arabic-speaking carers were also less concerned about dementia-related behaviors than the other 3 groups. Unlike carers from the other CALD communities, Chinese-speaking carers did not report worrying about the safety of the PLWD.

In discussing these findings, it should be emphasized that while some cultural groups did not mention certain issues, this does not necessarily indicate that these are not prevalent issues for their communities. For example, Arabic-speaking and Chinese-speaking carers may not have discussed gender as impacting caregiving, but this may have been due to an uncritical acceptance that family members of a certain gender provide care.

There are some similarities between the current findings and North American research with regard to Chinese-speaking and Spanish-speaking carers. Cultural piety and familism were identified as having an impact on families' decision making about caring in the current study. Comparisons can also be made with Anglo-Australian carers. Like Anglo carers, CALD families struggle with managing changes in the PLWD and worry about being unable to cope with the demands of dementia caregiving. The CALD carers in our study reported stress, as have Anglo caregivers.[4] However, it is noted by Janevic and Connell[8] that caregiving-related stress is not always similar across cultures, so caution is required in comparing these findings.

The research reported in this article has implications for practice and education. If CALD communities prefer to provide care at home, programs should be developed that enable carers to do so safely, in terms of mobilizing the PLWD as well supporting for carers themselves. Although Anglo carers are involved in visits and care planning with doctors,[4] CALD carers appear to adopt a more substantial role in helping the PLWD with doctors' appointments. Certain tasks, such as having to interpret doctor-patient or doctor-relative communication are likely to add to carers' stress. There are also the difficulties and ethics associated with using family members as interpreters. Clinicians dealing with family carers from CALD communities need to reflect on these issues and consider the ways in which they could possibly support such carers in the medical encounter. Clinicians also need to be prepared for the possibility of the involvement of multiple family members in caregiving decision making—a situation sometimes accompanied by conflict and emotion.[32]

One limitation of the study is that Anglo-Australians were not included, which would enable more direct comparisons between CALD and non-CALD family carers. Future research should also consider investigating the experiences and perceptions of other populations, such as CALD communities not included in this study. Another limitation of our study is the focus upon just 1 stakeholder group—family carers—within the wider family structure. It would be beneficial for further research to examine how the carers' experiences and perceptions, especially with reference to family disagreements and difficulties around decision making, compare and contrast with the perspective of other family members.

In conclusion, it appears from this qualitative study that the CALD carers from the Arabic-speaking, Italian-speaking, Chinese-speaking, and Spanish-speaking communities in Australia experience the physical and emotional work of caregiving as closely intertwined with cultural issues. In order to provide sensitive, supportive care, it is imperative that clinicians and other health professionals be aware of the specific cultural context of such caregiving and the barriers and challenges experienced by those providing care for a PLWD in such CALD communities.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was funded by a grant from the National Health and Medical Research Council Dementia Grants Program Round Two.

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