



## ORIGINAL ARTICLE

# The experience of structural burden for culturally and linguistically diverse family carers of people living with dementia in Australia

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## Abstract

Evidence suggests that family carers of culturally and linguistically diverse (CALD) people living with dementia experience higher stress and unmet need than the general Australian population. These disparities are often framed as the result of CALD communities failing to seek formal support. Challenging this, we draw on the concept of 'structural burden' to explore how the complexity of health and aged systems contribute to the burden that CALD carers experience. We conducted semi-structured interviews with 104 family carers for CALD people with dementia in Australia, followed by thematic analysis of transcripts. Additional to structural burdens encountered by the general older population, CALD carers faced challenges understanding Australia's Anglo-centric aged care system, locating culturally appropriate care and were required to translate the languages and operations of health and aged care systems into terms their family members understood. This burden was mitigated by the presence of ethno-specific organisations and other navigation support. Australia's aged care system has moved towards centralised governance and consumer-directed care provision. This system involves a confusing array of different programmes and levels, bureaucratic applications and long waiting times. Carers' encounters with these systems demonstrates how some CALD people are being left behind by the current aged care system. While ethno-specific services can reduce this burden, not all CALD groups are represented. Consequently, improving access to dementia care among CALD populations requires entry point and navigation support that is culturally appropriate and linguistically accessible.

## KEYWORDS

Australia, ethno-specific services, informal caregiving, system fragmentation, system navigation, migrants

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## 1 | INTRODUCTION

Providing informal care for a person with dementia can be challenging for anyone, regardless of background. However, people from culturally and linguistically diverse (CALD) backgrounds may face additional challenges when engaging with systems designed for the cultural and linguistic majority. Recent research highlights structural issues, including lack of culturally appropriate options, inadequate language support, sub-optimal care from GPs and complex and fragmented pathways, as barriers to engagement with formal dementia care (Baghirathan et al., 2020; Berdai Chaouni & De Donder, 2019; Bernstein et al., 2020; Brijnath et al., 2021; Carlsson & Pijpers, 2021; Lee et al., 2011; Nielsen et al., 2021). Navigating and accessing support often falls on older adult children, who are the key seekers and facilitators of formal care (Berdai Chaouni & De Donder, 2019; Czapka & Sagbakken, 2020; Nielsen et al., 2021), and may be required to perform language interpreting between their older parents and providers (Baghirathan et al., 2020; Mukadam et al., 2011; Shanley et al., 2012). Furthermore, older CALD people may feel mistrust towards formal services, arising from past experiences of discrimination or a lack of culturally appropriate services and assessments (Baghirathan et al., 2020; Carlsson & Pijpers, 2021; Goeman et al., 2016; Greenwood et al., 2015).

We draw on the concept of 'structural burden' to analyse the systemic sources of carer burden among CALD groups. Taylor and Quesnel-Vallee (2017, p. 20) define structural burden as 'a new dimension of carer burden that arises from managing complex interactions within the fragmented structures of formal health and social care.' As populations have aged in recent decades, health and social care policy have shifted caregiving responsibilities onto informal carers to meet the needs of increasing numbers of older people with long-term conditions such as dementia (Brijnath & Gilbert, 2022). Services along the dementia care pathway may be distributed between different organisations or government departments, with different eligibility criteria and applications (Gilbert et al., 2020). Service fragmentation can lead to responsibility shifting, inconsistent or conflicting advice, overlaps and/or gaps in service provision and poor continuity of care (Productivity Commission, 2017). Informal carers are often required to navigate the service landscape on the behalf of people with dementia, and then advocate when their needs are unfulfilled or unrecognised (Dalmer, 2020; Funk et al., 2019). Analysis of how structural factors contribute to the challenge of informal carers helps address the burdens that care systems create.

This study aims to provide insights on how structural burden affects informal CALD carers for people dementia. The study is based on a large sample of interviews, encompassing seven language groups. This affords scope to examine asymmetries and consistencies within and between CALD groups in Australia. Moreover, the timing of this study, conducted after Australia's *My Aged Care* portal was introduced, provides insights into some limitations of efforts to facilitate an accessible and integrated aged care system for CALD populations and identifies areas for improvement.

### What is known about this topic?

- Family carers of people living with dementia from CALD communities experience greater stress and unmet need than other carers
- Failure to seek help is often attributed as an underlying cause for this disparity.

### What this paper adds

- The fragmented and bureaucratic nature of Australia's health and aged care systems creates structural burdens for carers, more so in CALD groups.
- There are asymmetries of access among CALD carers, owing to discrepant availability of ethno-specific services and inconsistent support pathways.
- Carers perceived that much support relied on professionals' good will rather than being a feature of health and aged care systems.

## 1.1 | Australian context

CALD carers of people with dementia are more likely to experience unmet need and psychological distress compared with other informal carers in Australia (Temple et al., 2021; Temple & Dow, 2018). Nearly 30 percent of Australians aged 65 and above are first-generation migrants, mostly from non-Anglophone countries (Australian Institute of Health and Welfare, 2018). Up to 80 percent of aged care in Australia is unpaid informal care (e.g. by family, friends and neighbours) in the community (Temple & Dow, 2018). This is higher among CALD populations (Khadka et al., 2019), who are more likely to expect long-term family care than Anglo-Australians and less likely to use residential aged care (Shanley et al., 2012). Dementia is also estimated to be more widespread among some CALD populations, owing to a higher presence of risk factors such as low literacy, socio-economic disadvantage and cardiovascular disease (Steenland et al., 2016; Wong et al., 2021). Consequently, there is a large population of community-dwelling older people with dementia in Australia who were born overseas, require an interpreter, and are living with a primary family carer (van Weel et al., 2019).

Over three decades, Australia's Commonwealth Government has centralised governance of aged care under the auspices of the Department of Health. Before this, local councils provided governance and administration of most home care. Commonwealth centralisation and privatisation was legitimised as a response to regional inequities in the quality and availability of aged care (Productivity Commission, 2011; Smith, 2019). Yet privatisation of council services by corporate providers has been controversial (Russell et al., 2020).

*My Aged Care* was introduced in 2013, aimed at reducing the complexity of navigating aged care via a nationwide online access point. The *My Aged Care* website contains information about subsidies, assessments and aged care providers. It has been criticised for assuming users

are literate in English, and have internet access (Phillipson et al., 2019). A telephone service is also available, but this has been criticised for long wait times and poor service from operators, with access for non-English speakers dependent upon interpreter availability (Royal Commission into Aged Care Quality and Safety, 2019, 2021).

These systemic changes align with a shift towards 'consumer-directed care', whereby the Commonwealth Government provides individualised subsidies for aged care services delivered predominantly by commercial and non-profit providers (Henderson & Willis, 2020). This is designed to grant choice and flexibility to older people and/or their carers. However, as we have shown in cognate areas such as mental health, the neoliberal imperative to self-manage is infused within this rhetoric of choice (Brijnath & Antoniadis, 2016). Consumer-directed aged care has been criticised for burdening vulnerable or minority groups, who may lack the literacy or resources to manage their care (Brijnath & Gilbert, 2022; McCallum & Rees, 2017; Moore, 2021).

Accessing aged care can be slow. Government-subsidised home care packages are offered at four levels in Australia, based on assessed needs and subject to means testing. Wait times mean many older people are assigned lower level packages than needed, or must wait months for packages to become available (Hill, 2021). These issues prompted the Royal Commission into Aged Care Quality and Safety (2021) to call for a complete overhaul of aged care legislation. Improving navigation, availability and quality in aged care are currently policy priorities in Australia.

## 2 | METHOD

Data were gathered during the *Moving Pictures* project: a community co-designed digital video project aimed at increasing dementia

awareness among CALD communities in Australia. Curtin University Human Research Ethics Committee approved the project. From February to May 2018 and December 2019 to February 2020, bilingual research assistants conducted semi-structured interviews with 104 informal carers of people with dementia (See Table 1), from seven language groups: Chinese (Mandarin and Cantonese), Arabic, Hindi, Tamil, Greek, Italian or Vietnamese. Excluding Tamil, these represent the top eight languages other than English spoken in Australian homes (Australian Bureau of Statistics, 2017). Tamil participants represent Australia's growing South Asian population. We recruited participants by language rather than ethnicity or nationality, as the project's aim was to produce in-language digital videos. Moreover, in Australia, minority groups are typically defined by their cultural and linguistic diversity (CALD) rather than ethnicity (Pham et al., 2021).

### 2.1 | Recruitment

Carers were recruited through advertisements placed in community venues (doctors' clinics, aged care facilities and community organisations). We asked health and aged care service providers with high caseloads of eligible clients to distribute project invitations. Selection criteria were: speaker of one of the seven languages, a primary carer (i.e. providing regular direct assistance with communication, mobility and self-care) for a person with dementia for no less than 1 month during the past 12 months, over 18 years old, and capable of consenting to a video-interview. All carers provided formal written consent prior to being interviewed. All but two participants consented to be video-recorded, one to being audio-recorded and one to detailed notetaking during the interview.

TABLE 1 Demographic information about participating carers

Language group	Arabic (n = 17)	Chinese (n = 22)	Hindi (n = 8)	Tamil (n = 10)	Greek (n = 14)	Italian (n = 22)	Vietnamese (n = 11)
Women	11 (64%)	18 (82%)	5 (63%)	5 (50%)	9 (64%)	15 (68%)	9 (82%)
Mean age (SD)	55.6 (9.4)	61.8 (10.6)	58.9 (11.8)	58.6 (10.7)	62 (14.7)	61.9 (8.9)	58.8 (6.6)
Mean years as carer (SD)	5.1 (3)	6.8 (3.7)	5.9 (3.6)	6.2 (3.4)	6.9 (3.5)	10.6 (10)	4.5 (3.2)
Mean years in Australia (SD)	24.4 (16.3)	30.7 (12.5)	33 (15.7)	19.5 (5.7)	52.8 (8.1)	54.1 (11)	33.9 (9)
Cared for							
Mother	12 (71%)	11 (50%)	4 (50%)	1 (10%)	5 (36%)	12 (55%)	7 (64%)
Father	3 (18%)	1 (5%)	0	5 (50%)	3 (21%)	2 (9%)	1 (9%)
Wife	0	2 (10%)	1 (12.5%)	0	3 (21%)	0	1 (9%)
Husband	2 (12%)	5 (23%)	0	1 (10%)	1 (7%)	6 (27%)	1 (9%)
Mother-in-law	0	1 (5%)	1 (12.5%)	1 (10%)	0	2 (9%)	1 (9%)
Father-in-law	0	1 (5%)	1 (12.5%)	1 (10%)	0	0	0
Other	0	0	1 (12.5%) <sup>a</sup>	1 (10%) <sup>b</sup>	1 (7%) <sup>c</sup>	0	0

<sup>a</sup>Father's aunt.

<sup>b</sup>Sister.

<sup>c</sup>Grandmother.

## 2.2 | Procedure

Interviews were approximately 45 minutes in duration. Interviewers were given training and practice in qualitative interviewing by BB and J Antoniadis, both qualitative researchers experienced in working with CALD communities. Interview participants chose whether they spoke English or their selection language, often opting to blend languages. Interview questions prompted participants to recall their experiences with dementia care, uptake of formal support services and encounters with health and aged care services and staff. Interview recordings were transcribed and translated into English by the bilingual interviewers.

## 2.3 | Analysis

This was a primary analysis, however, the team was familiar with the interviews from producing the digital videos. AG, J Antoniadis and SC conducted coding in NVivo 12 (QSR International). We developed preliminary codes using NVivo's mind map feature, which already included codes like 'navigation', 'paperwork', 'information seeking', 'My Aged Care', among others. We tested inter-coder reliability on three transcripts and met periodically throughout coding. Codes were refined throughout, usually by combining or eliminating redundant or unused codes. However, we did not add many new codes to the framework. AG then grouped salient codes into larger themes, and provided examples and quotations for each theme. BB and J Antoniadis reviewed this and provided detailed feedback. AG then revised the themes and selected the most appropriate examples and quotations. AG and BB authored the manuscript, with feedback from the whole team.

## 3 | FINDINGS

Findings are organised into subheadings, representing each key theme: 'Navigating fragmented systems', 'Managing language barriers', 'Challenges accessing aged care', 'Compensating for gaps in care' and 'Finding support'. All data are anonymous. Participants are identified by pseudonym, age bracket, language spoken and care relationship.

### 3.1 | Navigating fragmented systems

Navigating Australian health and aged systems were a challenging experience for carers, with fragmentation between services being a source of structural burden. Many carers felt service providers only took responsibility for their narrow specialisation, leaving it to them to coordinate care and compensate for any gaps.

*It's been a horrible journey. There have been some people who have been very helpful and others that have not been so helpful [...] It's very complex, very emotionally draining. Like, we just got shunted from one organisation*

*to another. [Francesca, 60–69 years, Italian-speaker, cared for Mother].*

Even after a family member was diagnosed with dementia, there could still be a lack of clarity from doctors about post-diagnostic support. Recent migrants, in particular, were unaccustomed to and confused by Australia's health and aged care systems. Some doctors provided prescriptions for medications or treatments, but offered little guidance about daily caregiving. As carers' parents or grandparents often resided in different countries, many carers were unfamiliar with providing aged care and figure out caregiving on their own (Brijnath et al., 2021).

*See the diagnosis was not very helpful [...] I was the translator because Amma could not speak English. So the lady would ask questions and Amma was really good with maths... She was asking, 'Tell this, tell that', they have a standard procedure, and she said 'Yeah, she's got dementia'. There was nothing that they said, 'Yep, she's got dementia' and then came back to us with a plan... It was a one off thing. They said 'She's got dementia' and that's it, full stop. [Anushka, 50–59 years, Hindi-speaker, cared for Mother-in-law].*

Carers said that information about services tended to be dispersed, and required legwork to access. Those who spoke English recounted spending significant time and resources researching dementia, treatment and care options, eligibility for government assistance and applications.

*If you are able to use the internet, you can go to My Aged Care, and maybe even go to various groups such the [Italian community service] or to the doctor who can give out information. But, for example, there is no centralised point where if you go there, they give you all the information. You have to enquire a little here and a little there. [Giulia, 40–49 years, Italian-speaker, cared for Mother].*

Seeking information was especially challenging for carers who were not educated in Australia, lacked English literacy or unfamiliar with Australia's care systems. Recently arrived migrants or older spousal carers often struggled with the formal language and bureaucratic complexity. These carers were much more dependent on others for navigation support.

*Each time I would read more, I felt like I needed a University degree to read everything that was available because the language was fairly sophisticated and it was quite difficult for me to understand, which prompted me to consider not only our older [Greek-born] parents who may not understand it, but also the children who also may not know or have not a level of education to support*

*this understanding. [Ioanna, 60–69 years, Greek-speaker, cared for Father].*

Even carers who were Australian-educated found system navigation intimidating. Some worried about other older people in their CALD community who did not have English-proficient and educated people in their support network.

### 3.2 | Managing language barriers

Many carers felt that their older relatives with dementia were disadvantaged compared with English-speaking older Australians. For example, even when families did engage with dementia support groups or homecare services, these services often had English-speaking staff and were therefore of limited use:

*I was the person who had done all that work. Even though we booked them, they came but could not do anything [...] To someone who is not Vietnamese, who can speak English [...] there are services for dementia people. The service provides people to come and help at home. However, it is not, to Vietnamese people, there is limited service. [Thanh, 50–59 years, Vietnamese-speaker, cared for Father].*

Carers also felt they had to advocate for their family member, because limited English and health literacy, combined with dementia, meant they were disempowered when dealing with mainstream services and not in a good position to advocate for themselves:

*We must be advocates for our parents. An example: mum felt sick again and we had to take her to the hospital and they put her in the ward for a night [...] You have to often tell them how to handle things because you know your family member or your relative. They only see them on that occasion. You must always be the one who manages what happens and if you see that something is not right, you must find another way. [Giulia, 40–49 years, Italian-speaker, cared for Mother].*

Carers in our study were usually more proficient and literate in English than the family member for whom they provided care. This meant they were often required to translate information or interpret what doctors, aged care assessors, care workers and other service providers said. Some carers criticised the expectation that they interpret, arguing it would be more appropriate to use professional interpreters during appointments with professionals.

*The lady did not speak to my mother but to me [...] It would have been better to have an interpreter, because my mother talked to me as a daughter and not as an interpreter. In my opinion, there was this difficulty,*

*both with the lady of ACAT [Aged Care Assessment Team] who was very good and kind, but who spoke to me instead of my mother and secondly to my mother who again spoke to me and not to the lady [...] But there was no choice, there was no possibility of having an interpreter. [Cristina, 70–79 years, Italian-speaker, cared for Mother].*

Interpreting technically complex or emotionally difficult information was often challenging. Carers felt it assumed a level of skill and responsibility they were not prepared for, prompting concerns that their mistakes could affect their relative's access to aged care or treatments.

### 3.3 | Challenges accessing aged care

Carers encountered various difficulties accessing the *My Aged Care* portal. Many said it placed the onus of navigation onto older people or carers. This was problematic for non-English speakers, as the portal had not been developed with their needs in mind.

*Sometimes I call [My Aged Care] to ask them for information because I cannot understand how to go through the procedures. However, I felt like I was talking to my superiors [...] Vietnamese should be included and appear on the front page of information resources about support for dementia patients. They open the screen and log on to the My Aged Care website; they want to see the information in Vietnamese. [Pearl, 50–59 years, Vietnamese-speaker, cared for Mother].*

Sometimes aged care assessments lacked cultural relevance or cultural sensitivity. Assessors advised many families to admit a person with dementia to residential aged care. However, carers considered this unhelpful, as the purpose of organising an assessment was to seek support to enable the person with dementia to remain at home.

*I went looking and finding the information, but again, applying that information to our culture; that was not possible for us. So, you know if someone was able to understand our culture and give us the right advice; that would have been good [...] Wherever we went, everywhere, the response was 'nursing home', and as soon as we heard that, 'nursing home', for us, the way we were brought up, nursing home wasn't an option. [Savitri, 50–59 years, Tamil-speaker, cared for Father].*

Rules around gaining the person with dementia's consent to undertake an assessment created other cultural tensions between carers and aged care assessment services. Some carers said that in their culture, it did not make sense to require formal consent for an assessment by an older person if their dementia was advanced. Many argued that they knew what was best for their relative

and that their relative lacked the capacity for informed consent anyway.

*You know privacy issues are important but not major in the Indian context. Sharing information with the family is important and with a dementia patient, if you ask 'Do you want to share information with your family?', he would not know how to say 'yes' or 'no', because for him it's a given that you would be sharing information. [Ravi, 50–59 years, Tamil-speaker, cared for Father].*

*It is such a stupid system [...] I made a referral to My Aged Care, in January this year, 5 months [ago]. They said they cannot work on it, they need her consent. I said she cannot give consent, she's got dementia, she does not speak English, she's hard of hearing; I do not know how you are going to get the consent. So, they said they cannot proceed. [Jasmeet, 60–69 years, Hindi-speaker, cared for Mother].*

Consequently, carers said it was important to arrange enduring power of attorney ahead of time, before a person's dementia was too advanced. When families failed to do this, assessors were uncompromising about requiring the older person's consent, which could delay aged care assessments and applications.

### 3.4 | Compensating for gaps in care

Some of our participants had been carers prior to the introduction of *My Aged Care* and were able to contrast their prior experiences receiving home care from local councils to their experiences with the Commonwealth's current centralised system. Typically, local councils were described as having been more responsive, flexible and sensitive to the particular needs of older people, and better networked with community-level ethnic organisations than the new system.

*When Mum had the assessment in [a Melbourne suburb] and the council was the provider, [...] it was all laid out. I had respite, I had cleaners. It was great. I did not have any issues. The council now are cutting back on funding because of My Aged Care. A lot of things have taken over. [...] We had some issues with My Aged Care for Mum as they lost her assessment, so we had to wait 14 months to get the funding. That was a problem. It was hard, it was really hard, as I spent 2–3 hours over the phone for bureaucratic stuff. [Gianna, 50–59 years, Italian-speaker, cared for Mother].*

The issue of wait times under *My Aged Care* arose frequently. Some carers were still waiting for home care packages at the time of the interview, and expressed concern that their relative might

die before the package came through. While they waited, families often had to pay for home care privately, or the carer reduced their employment to provide informal care, both of which incurred financial cost. Carers also voiced criticisms of *My Aged Care* for failing to clearly inform them about what home care packages included. Some carers reported that they had missed entitlements that could have addressed some aspect of need due to poor communication from providers.

*There are many things that I did not [know] about the package and discovered them at the end. I did not understand what the package pathway exactly covered. It is not only necessary to pay from this package to the care attendant, but you can buy other things like buying a machine to grind food. I did not know that [...] There are many things that they do not explain. They are supposed to tell us that there are these services. [Lydia, 50–59 years, Arabic-speaker, cared for Mother].*

Carers also criticised the lack of transparency about how home care providers handled packaged funds. Providers were accused of offering poor value for the funds they took, and imposing excessive administrative costs. Consequently, despite being on high-level home care packages, some carers said they still had inadequate time for respite. There was an evident lack of transparency in the way aged care packages were allocated by government and delivered by providers.

*According to the current system [older people] do not get as much as what the government funds. A person who is at level 4 package can get quite a lot of funding, not a little. It means, for example, they can get A\$60,000 per year. With that funding, if we have to go through a group that is responsible for paperwork and a group that is responsible for carers, between these two groups, [...] the paperwork takes 13% commission of the package. Then, the carer group takes another layer of expenses. Therefore, when it reaches [older people], they have only 10–12 hours a week. [Thanh, 50–59 years, Vietnamese-speaker, cared for Father].*

Coming from a CALD background could accentuate these burdens. Carers said their ability to choose between providers were limited by a need to find culturally appropriate care. Moreover, those with low English literacy or limited education found the home care package system difficult to comprehend, and were not confident about shopping around or negotiating terms with providers.

### 3.5 | Finding support

Despite these challenges, many carers found sources of support with system navigation. Often these sources were individual

professionals, including geriatricians, GPs, social workers, nurses, aged care workers and aged care assessors. These people informed families of where to go for help, made appointments on their behalf, explained care options and filled out application forms.

*[She] is the one who did for us the paperwork for Housing Commission; she filled them out and completed them by going to the family doctor, pharmacy as well as the specialist. She told me, 'Because you can't do it by yourself, so I will do it for you'. She filled out all the papers, all the papers done by her. But unfortunately, when we dropped them to the Housing Commission, they requested new papers. I am also not able to do it. [Dalia, 70–79 years, Arabic-speaker, cared for Husband].*

*Fortunately, the lady who was my case manager [at a mainstream home care agency] was great. She's now a good friend. She was my person to call for anything. She would go out of her way to help with anything. Not everyone would do it. [Anushka, 50–59 years, Hindi-speaker, cared for Mother-in-law]*

Often, supportive professionals worked at ethno-specific services or otherwise shared the same cultural and linguistic background as the carer. These individuals were able to act as 'boundary-crossers' (Brijnath et al., 2022), bridging the cultural and linguistic divide between the lifeworld's of older people and their carers on the one hand, and health and aged care bureaucracies on the other. Sometimes these individuals were well known within their community to provide families with knowledge and assistance when a family member was diagnosed with dementia.

*She [Chinese community worker] knows my father's condition and knows how they can help him, very knowledgeable in that. If she does not have anything, she will tell me to contact certain government service... So she has a lot of information and knowledge where I can get help. [Xihe, 60–69 years, Chinese-speaker, cared for Father].*

Carers among the Chinese-, Greek-, Italian- and Vietnamese-speaking samples mentioned using a range ethno-specific and community organisations. This was less evident in the Arabic-speakers' interviews. Some Tamil- and Hindi-speakers reported that they had sought or organised support through local Gurudwaras or temples. However, they also reported that there was a deficit of ethno-specific aged care services catering to them.

*There is Italian provider and Italian nursing homes. Maybe time coming for Indian nursing home, with Indian food, Indian culture, Indian people working there and*

*talking. [Jasmeet, 60–69 years, Hindi-speaker, cared for Mother].*

Ethno-specific services often provided home care, respite care and residential aged care. They also hosted support groups, translated information, made medical or allied health referrals, organised transportation and offered guidance in applying for government services:

*They [Vietnamese community organisation] have helped me learn a lot of information. For example, [a community worker] helped me get transportation services for my husband, with a wheelchair free of charge. They instructed me on the diapers to use for my husband. I now know about better diapers and better absorbency. Since then, I feel that I have no difficulty taking care of him. [Jenny, 50–59 years, Vietnamese-speaker, cared for Husband].*

It was evident that such organisations were important for facilitating entry and navigation of services, thereby providing an integrated care pathway (Goeman et al., 2016; Kim & Silverstein, 2021; Radermacher et al., 2009). Moreover, these organisations were often well established and already familiar older CALD people and their families, which sometimes made it easier for carers to discuss formal care options with a reluctant older relative.

## 4 | DISCUSSION

Providing dementia care is challenging for anybody, not just people from CALD backgrounds (Bernstein et al., 2020; Miller et al., 2019). Many challenges presented above are also encountered by the Anglo-Australian majority, including wait times and poor transparency around home care packages (Day et al., 2017; Royal Commission into Aged Care Quality and Safety, 2019, 2021; Russell et al., 2020). We argue that these burdens are amplified for CALD older people and their carers in ways not experienced by the Anglo-Australian majority. However, these disparities are not dichotomised only between CALD- and Anglo-Australians, but also manifest differently between CALD groups. Differences in education and literacy, socio-economic factors, migration histories and culture means there are significant asymmetries between cohorts of CALD older people and carers (Greenwood et al., 2015; Koehn et al., 2012).

Across all participant languages, and consistent with the international literature (Czapka & Sagbakken, 2020; Greenwood et al., 2015; Nielsen et al., 2021; Parveen et al., 2017), CALD carers perceived language to be a major barrier. This manifested in different ways. Often while CALD older people had limited English proficiency, their adult children carers were highly literate in English. This occurred in all groups, but was the typical profile of Greek- and Italian-speaking carers, as these groups had lived longest in Australia and carers had usually completed formal education in Australia. These carers

assumed the responsibility of overseeing, managing and translating access to care on behalf of a parent who had difficulty comprehending and engaging with Anglo-centric services. By contrast, for carers with limited English literacy, structural burdens were more formidable. These were generally spousal carers, recent migrants or carers with limited education. In our sample, limited English literacy and education were most evident among Vietnamese- and Arabic-speakers.

Consistent with international literature, this latter group reported having a limited prior understanding of dementia and found health, aged care and welfare systems uncompromising and inhospitable (Baghirathan et al., 2020; Berdai Chaoui & De Donder, 2019; Czapka & Sagbakken, 2020). They also found *My Aged Care* challenging to navigate, and information about aged care assessments, home care packages and application progress bureaucratic and assuming of a high level of English (Royal Commission into Aged Care Quality and Safety, 2021). Many relied on the good will of supportive professionals, especially after recent dementia diagnoses or when lodging applications. This was perceived to be supererogatory support, occurring against a backdrop of a bureaucratic and uncaring system. Where such support was not available, the older person's and/or the carer's needs could remain unmet.

Prior research has attributed low participation in formal services among people from CALD backgrounds to preferences for culturally familiar institutions and services, and unfamiliarity with or trepidation about utilising mainstream services (Baghirathan et al., 2020; Mukadam et al., 2011; Parveen et al., 2017). Ethno-specific aged care services have a long history of catering to these preferences in Australia (Runci et al., 2014; Westbrook & Legge, 1992). Ethno-specific and multicultural providers also act as 'boundary crossers' (Brijnath et al., 2022), who facilitate access to medical care, aged care and other forms of support (see also Carlsson & Pijpers, 2021). In Australia, there exists a legacy of ethno-specific and multicultural services, many having been established in a period of generous Commonwealth Government investment in aged care during the 1970s (Westbrook & Legge, 1992). This differs from comparable countries, such as in Western Europe, where the presence of such services is comparably lower (Berdai Chaoui & De Donder, 2019; Czapka & Sagbakken, 2020; Nielsen et al., 2021). Nevertheless, access to ethno-specific services is unequally distributed between CALD groups, being more common for groups with longer migration histories and larger populations in Australia, such as the Chinese, Greek and Italian communities (Wilson et al., 2020). More recent or smaller migrant groups, without well-established and well-organised communities in their destination country, tend to be disadvantaged by a lack of community-level support.

#### 4.1 | Policy implications

In Australia and internationally, there is a desire for integrated models of care that provide holistic pathways that reduce the

structural burden experienced by older people and their carers (Dodd et al., 2022; Gilbert et al., 2020; Mann et al., 2020). Such pathways should recognise and attend to the needs of CALD communities (Bernstein et al., 2020; Carlsson & Pijpers, 2021; Goeman et al., 2016), not only focusing on ethno-specific services (Radermacher et al., 2009), but also communication between CALD groups and mainstream services (Brijnath et al., 2022). This seems especially pertinent regarding carers' comments about the consent and privacy requirements of an older person undergoing assessment. Wider literature suggests that Western conceptions of privacy and consent are underwritten by individualist values, which may conflict with relational or collectivist value systems (Bentwich et al., 2018; Ho, 2008). Notwithstanding, transferring power of attorney can be legally fraught once an older person's dementia has already advanced, regardless of cultural and linguistic background (Webb, 2021). Yet delayed detection and diagnosis of dementia, language barriers and unfamiliarity with Australian laws, can make this especially difficult for CALD families. It is important to communicate these requirements to families early, so older people and their carers can prepare for such eventualities ahead of time.

In countries such as the Netherlands, the UK and Germany, neighbourhood governance models are attuned to situational realities of minorities, and cultivate local relationships and networks that facilitate equitable pathways to health and aged care (Carlsson, 2021; Carlsson & Pijpers, 2021). Australian aged care reform has moved in the opposite direction, centralising governance and privatising service provision, while assuming service gaps will be addressed by markets (Dyer et al., 2020; Henderson & Willis, 2020). The Royal Commission has prompted initiatives to address deficiencies in Australia's consumer-directed approach, including for CALD communities. The Commonwealth government, recognising the limitations of a consumer-directed care model in such 'thin markets', has moved to trialling a network of system navigators to support CALD older people's access to *My Aged Care* and other services (Skatssoon, 2021). This approach works around, rather than addressing, entrenched systemic issues around accessibility. While efforts are underway to reduce systemic barriers, their solutions and outcomes remain to be seen.

#### 4.2 | Strengths and limitations

The large sample size ( $n = 104$ ) and diversity of CALD backgrounds included in this study meant a wide range of different experiences and biographies were gathered. Moreover, employment of bilingual interviewers, fluent in both English and other languages, meant interviews could be adapted to participants' language preferences and non-English proficient participants could be interviewed. A limitation is that we did not interview care recipients. We acknowledge family carers may underestimate the capacities of people with dementia (Miller et al., 2019). Nor can we report on older people who do not have the benefit of family carers. Data collection occurred within a multimedia project aimed at raising dementia awareness in



CALD communities. Participants were aware of and likely endorsed the project aims, and recruitment may have excluded carers who do not accept Western medical understandings of dementia, have never sought formal dementia services, are distrusting of service professionals, hold stigmatising attitudes or fear disclosing their relative's illness to others (Mukadam et al., 2011). The nature of our project meant our selection criteria preference Australia's largest CALD communities. Moreover, some carers were recruited through ethno-specific services that we argue alleviated their structural burden. Carers from smaller CALD communities, or those living in parts of Australia that are not well serviced by ethno-specific organisations, such as outside major cities, may have different experiences.

## 5 | CONCLUSION

Improving navigation, access and quality in aged care is currently high on the Australia's political agenda. The Royal Commission has rightly recognised informal carers compensating for gaps in the system, and that better support and resourcing for them would mean a more responsive and efficient aged care system overall (Deloitte Access Economics, 2020; Royal Commission into Aged Care Quality and Safety, 2021). This article has applied the concept of 'structural burden' to examine how health and aged care systems burden people with dementia and carers from CALD backgrounds. We suggest that establishment and strengthening of community-level support catering to those CALD communities most in need should be part of any future reform.

### AUTHOR CONTRIBUTIONS

BB, J Adams, DG, CB, MK, KE, J Antoniadis conceived of and designed the project. J Antoniadis was the project manager. BB, J Antoniadis, AT, SC gathered study data. ASG, J Antoniadis SC and AT conducted qualitative data analysis. ASG and BB wrote this manuscript. All authors reviewed this manuscript before submission.

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### DATA AVAILABILITY STATEMENT

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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