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RESEARCH ARTICLE

Dementia care for people from culturally and linguistically diverse backgrounds: Qualitative secondary analysis of the Aged Care Australian Royal Commission data

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Abstract

Objective: Understanding the concerns and experiences of people living with dementia from culturally and linguistically diverse backgrounds is critical to ensure culturally appropriate care is delivered. This study aimed to describe the current experiences and concerns of older people from culturally and linguistically diverse backgrounds using the publicly available evidence from the Australian Royal Commission into Aged Care Quality and Safety.

Methods: This was a qualitative secondary analysis of the Australian Royal Commission into Aged Care Quality and Safety data to explore new and nuanced insights about care for culturally and linguistically diverse people living with dementia. Using the keywords to search the data corpus, we extracted a topic-specific data set focused on dementia care and cultural diversity. Thematic analysis was used to identify and describe the present practices and challenges.

Results: Our findings showed that the need for cultural connection for older people from culturally and linguistically diverse backgrounds increases as dementia progresses. Access to culture-specific food and music facilitated connection with their culture of origin. Many older people from culturally and linguistically diverse backgrounds with dementia reverted to their language of origin; however, the inability to communicate due to a lack of language support impacted their health and well-being, and care provision.

Conclusions: Further work is needed to provide the necessary cultural experiences and language support to ensure comfort and equity in the provision of dementia care for Australians from migrant backgrounds.

KEYWORDS

aged, Australia, cultural diversity, dementia, transients and migrants

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1 | INTRODUCTION

Dementia is a progressive, incurable neurodegenerative disorder that significantly impacts the person living with the condition and the people who support them.¹ In Australia, over 400,000 people are living with dementia and this number is projected to double by 2058.² In 2019–2020, 54% of people living in residential aged care (RAC) had dementia.² In 2018, 28% of Australians living with dementia were born in non-English-speaking countries,² a number which is also projected to increase.³ As of June 2021, 9% of all people using RAC in Australia preferred to use a language other than English.⁴ Caring for people living with dementia is complex, and for older people living with dementia who have taken on a second culture and language, care may be further complicated as people may revert to using their first language for communication⁵ and experience increasing cultural disconnection⁶ as dementia progresses. A systematic review of the experiences of older immigrants living with dementia identified very few studies yet highlighted several challenges including a lack of culturally safe services, language barriers and experiences of stigma.⁷ Clearly, older immigrants living with dementia are underrepresented in research⁸ and further exploration of the impact of culture and language in dementia care for older people from culturally and linguistically diverse backgrounds is warranted.

The Australian Aged Care Quality Standards require providers to ensure that care and services recognise and respect cultural differences and are culturally safe.⁹ Ensuring access to culturally appropriate care (e.g. care staff from a similar cultural background) and language supports (e.g. bilingual staff, translators) for people living with dementia are key components of culturally safe care.¹⁰ Culture-specific dementia care has started to emerge in several countries including Sweden and Norway,¹¹ as well as in Australia.¹² This means that people living with dementia from culturally and linguistically diverse backgrounds have access to culturally familiar food, can maintain traditional practices, practice religious activities and communicate in their first language. Such specialised care acknowledges the need for culture and language to be integrated into person-centred care.

In Australia, following public accounts of inadequacies in the aged care sector,¹³ the Governor General established a Royal Commission into Aged Care Quality and Safety (Royal Commission) in 2018. The terms of reference authorised the Royal Commission to inquire into matters relating to the challenges and opportunities facing older people, and the role of related partners in the delivery of care services for this population.¹⁴ The Royal Commission Final Report recommended ensuring dementia-friendly

Policy Impact

For older people from culturally diverse backgrounds living with dementia, the need for cultural connection increases as dementia progresses. The existing mainstream aged care services may incorporate cultural and linguistic diversity within dementia care provision for this population.

Practice Impact

For older people from culturally and linguistically diverse backgrounds, an inability to communicate due to a lack of language support impacted their well-being. Care providers and families need to ensure language support for people who have lost their English language due to dementia, including calling in relatives to assist when there is a breakdown in communication.

infrastructures, adequate post-diagnosis support pathways, and staff training on dementia and cultural safety.¹⁴ However, the Royal Commission did not provide specific recommendations for improving dementia care. In this study, we go deeper into this topic and re-examine the evidence presented from a scholarly perspective, as opposed to the legalistic framework of the Royal Commission. We aim to describe current experiences and concerns of people living with dementia from culturally and linguistically diverse backgrounds as reported by their families, and to identify specific recommendations for care improvement that impact policy and practice.

2 | METHODS

2.1 | Study design

A critical realist epistemology underpinned our qualitative descriptive analysis. Critical realism is effective for exploring complex social conditions¹⁵ and describing the complexities of care.¹⁶ This was a qualitative secondary analysis¹⁷ of publicly available evidence from the Royal Commission. The secondary analysis allowed us to maximise the use of the existing data,¹⁷ especially with the hard-to-reach populations such as people living with dementia from culturally and linguistically diverse backgrounds. It was also cost-effective to use the existing data as we would never have the capacity to replicate this work of the Royal Commission. Before undertaking

this study, we approached the Office of the Royal Commission and gained their approval to use the documents available on their website for scholarly analysis. This study was also approved (2021-03079) by the Human Research Ethics Committee of the Edith Cowan University, Western Australia. To protect the identity of the informants, and in line with the Association of Internet Researchers guideline,¹⁸ the names of the individuals and institutions are not reported in the findings.

2.2 | The data

The Office of the Royal Commission has made over 10,000 documents publicly available on its website.¹⁴ For this study, we identified and analysed documents most likely to reflect the lived experience of our population of interest and these included: general submissions from the public, workforce and providers (1183 items); diversity in aged care submissions by peak bodies and reflecting the interests of underrepresented groups and individuals (58 items); verbatim hearing transcripts and post-hearing submissions where selected witness statements were presented and informants questioned (227 items); and exhibits which included a range of supporting documents (5712 items). Due to the size of the data corpus, we first needed to isolate content fit for answering our research aim. Using extant literature and researcher experience, we compiled a list of 48 keywords relating to dementia and cultural diversity (Table 1). Using NVivo, we individually searched the data corpus for each of the keywords¹⁹ to identify relevant documents and content, an approach previously used to analyse Royal Commission data.²⁰ Highlighted content was then reviewed to create a smaller topic-specific data set inclusive of content from all available sources and relevant to our research topic. All data sources were considered equally important.

2.3 | Data analysis

Thematic analysis²¹ was used to identify and analyse themes. An inductive approach was taken as the coding was data-driven and not influenced by pre-existing coding frames or theoretical frameworks. We recognised the commonalities and prominent patterns as well as the more subtle and nuanced disclosures in both the explicit and latent content. Our critical analytical approach allowed us to highlight assumptions underlying care provision and the impact on lived experience throughout the analysis. To enhance the rigour and trustworthiness of the analysis, we read the topic-specific data set for familiarisation before inductive coding began and the

process of coding and theme development involved discussion and consensus among all authors. We referred to the data to ensure ideas, concepts, and relationships were contextually driven²¹ and used participant quotes to ensure findings were grounded in the data.

3 | RESULTS

We identified five themes: (1) culture is crucial as dementia progresses; (2) a strange new world; (3) culture delivered in doses; (4) loss of English is not a loss of language; and (5) neglecting opportunities and alternatives.

3.1 | Culture is crucial as dementia progresses

Older people from culturally and linguistically diverse backgrounds living with dementia do not lose their culture. Instead, as dementia progresses and access to more current memories diminishes,¹ old memories of younger days and previous homelands can be recalled. A family member expressed how the progression of their father's dementia had seemed to strengthen their father's desire for meaningful cultural connections:

He was connected to his culture in that he was connected to his brother and he was connected to his family but he wasn't traditional in what most people would be, but as he got – as his disease progressed, he became more connected with his culture.

(Hearing Transcript)

Another family member reported the importance of cultural engagement for their parent and how the lack of it could effectively sever their parent's remaining connection to the past and present earlier than was necessary:

...Without these familiar sensations, and with the saturation of irregular cultural practices and sensations, vulnerable elders can close off from their surroundings and stop engaging with the world a lot earlier during the progression of their disease than if otherwise culturally engaged.

(Exhibit)

The evidence in this theme identifies that older people from culturally and linguistically diverse backgrounds retain earlier memories of a different cultural life. To some degree, people may be connected only with their past

TABLE 1 Keywords and search results (number of documents and mentions) for general submissions, hearing transcripts and post-hearing submissions, exhibits and diversity in aged care submissions.

Keywords	Extra details	General submissions (<i>n</i> = 1183)		Hearing transcripts and post-hearing submissions (<i>n</i> = 227)		Exhibits (<i>n</i> = 5712)		Diversity in aged care submissions (<i>n</i> = 58)	
		Documents	Mentions	Documents	Mentions	Documents	Mentions	Documents	Mentions
Africa*	Africa/African	3	3	5	6	1	2	6	23
Agitation		5	6	28	83	4	6	0	0
Aggress*	Aggressive/aggression	0	0	59	175	5	17	5	6
Alzheimer*		8	14	46	184	3	8	8	18
Asia*	Asia/Asian	2	4	7	10	1	60	7	14
Arabic		0	0	3	13	1	11	4	21
BPSD	Behavioural and psychological symptoms of dementia	3	3	18	36	2	7	18	208
“Born overseas”		2	3	4	9	1	2	6	16
Cantonese		0	0	0	0	0	0	4	8
Culturally and linguistically diverse		6	17	19	166	2	87	18	208
China		0	0	8	29	0	0	4	7
Chinese		2	12	6	9	1	1	10	95
“Cognitive decline”		10	16	24	62	2	2	5	10
“Cognitive disorder”		0	0	0	0	0	0	0	0
“Cognitive impairment”		8	17	56	162	1	1	14	31
“Culturally appropriate”		4	5	21	60	3	3	32	186
“Culturally sensitive”		2	9	4	4	1	1	6	9
“Cultural safety”		2	6	14	106	1	1	6	9
“Culturally and linguistically diverse”		17	36	25	41	3	7	23	90
Dement*	Dementia/demented	65	469	152	3320	8	221	38	260

TABLE 1 (Continued)

Keywords	Extra details	General submissions (<i>n</i> = 1183)		Hearing transcripts and post- hearing submissions (<i>n</i> = 227)		Exhibits (<i>n</i> = 5712)		Diversity in aged care submissions (<i>n</i> = 58)	
		Documents	Mentions	Documents	Mentions	Documents	Mentions	Documents	Mentions
Emigra*	Emigrants/emigrant/ emigration	1	1	0	0	0	0	0	0
England		2	3	26	111	0	0	5	8
Ethnic*	Ethnic/ethnicity	25	91	15	56	3	13	18	218
Ethno-specific		2	14	4	21	1	1	7	90
Europ*	Europe/European	5	12	30	41	2	2	11	31
Foreign-born		0	0	0	0	0	0	0	0
Forget*	Forget/forgetful/forgetting	6	13	57	123	3	8	4	8
Greek		0	0	8	36	3	23	5	56
Hindi		1	1	0	0	0	0	1	1
Immigra*	Immigrant/immigration	1	7	9	14	1	2	10	32
India		1	2	9	11	0	0	3	7
Italian		2	7	18	43	2	11	8	53
Italy		1	2	11	15	1	2	2	5
Language		22	58	84	478	7	38	32	235
“Lewy body”		0	0	9	36	1	2	0	0
Malaysia		0	0	1	1	1	1	1	3
Mandarin		0	0	0	0	0	0	4	9
Middle-east*	Middle-eastern countries	0	0	0	0	0	0	1	1
Migra*	Migrant/migration	7	26	38	117	3	16	20	115
Multi-ethnic		1	5	0	0	0	0	0	0
Multicultural		5	17	9	17	2	3	9	211
“Muslim countries”		1	1	0	0	0	0	0	0
“New Zealand”		3	6	46	192	2	3	7	10
Non-English-speaking		13	22	8	8	1	1	13	89
Overseas-born		0	0	2	4	1	3	3	8
Philippines		0	0	4	4	0	0	2	4
“Psychological distress”		2	20	3	4	0	0	2	2

(Continues)

TABLE 1 (Continued)

Keywords	Extra details	General submissions (n = 1183)		Hearing transcripts and post-hearing submissions (n = 227)		Exhibits (n = 5712)		Diversity in aged care submissions (n = 58)	
		Documents	Mentions	Documents	Mentions	Documents	Mentions	Documents	Mentions
Punjabi		0	0	0	0	0	0	1	20
“Quality of life”		27	142	112	485	4	13	25	76
Refugee		1	1	2	3	0	0	5	11
“Second language”		2	3	9	14	1	2	3	4
Spanish		1	1	4	7	0	0	2	3
South Africa		0	0	1	1	1	1	2	3
Sri Lanka		0	0	2	7	2	5	2	10
Tagalog		0	0	1	1	0	0	0	0
Vietnam		1	1	4	39	0	0	3	15
Vietnamese		0	0	3	11	0	0	5	7
Wander*	Wander/wandering	2	18	48	243	3	11	1	1
Total search counts		262	1071	935	6126	72	541	370	2322

culture, and this connection strengthens as dementia progresses, making such connections important to preserve. Where care provision assumes that culture and personal history are no longer relevant for people with dementia, options to connect to culture are not made available. Family recognised the importance of maintaining such connections and were concerned about the impact that a lack of opportunities for meaningful engagement could have on premature and avoidable withdrawal and isolation.

3.2 | A strange new world

This theme centres on the way older people from culturally and linguistically diverse backgrounds experienced living in a care facility as a strange new world where everything was different and unfamiliar. This experience effectively intensified the losses already experienced due to dementia. Family members reported the various ways that their loved ones felt strange and disconnected from their culture:

The food, it's different; the language, it's different; and if the person with dementia of CALD background goes into respite or residential facility and there is no ethnic-specific care available, that person, it's totally lost, partly because of dementia and partly because nobody understands them.

(Hearing Transcript)

When they go into residential care facility ... a lot of people from different cultures feel that they are not wanted or welcomed at home. But, on top of all that, there is the food that he doesn't recognise.

(Hearing Transcript)

Family members believed that the unfamiliarity of the care environment compounded the feelings of insecurity associated with being moved into RAC facilities and the uncertain feelings associated with dementia. A family member articulated how their mother felt uncomfortable receiving care in an unfamiliar situation:

My mother may also be getting agitated because she had male carers attending to her personal care. When male carers would come in, she would cover herself up. This I believe is a cultural issue ...

(Exhibit)

The extracts above illustrate a deepened level of disconnection. Firstly, living in a different culture and then living with dementia in RAC with no ethnic-specific care created a set of circumstances, unrecognised or underestimated by care providers that appeared to exacerbate the agitation, loss and confusion typically associated with a move to RAC for someone living with dementia.²²

3.3 | Culture delivered in doses

Our third theme describes how culture-specific activities produced “cultural moments” and how dedicated cultural activities facilitated reconnection to culturally rich memories. A submission from a non-profit organisation gave the following example of how a culture-specific musical session delivered for an older woman living with dementia enabled her to recall and experience memories from her younger days in her culture of origin:

I haven't heard these songs since I was a little girl ... I was reliving my youth and my life in my village. Thank you.

(Diversity in Aged Care Submission)

Similarly, language support provided by a volunteer once a fortnight gave one resident the important opportunity to communicate in his first language:

... An Arabic-speaking volunteer was arranged to come and see Dad every two weeks. This organisation provides volunteers that speak another language for people whose English is their second language. This was helpful because at least once a fortnight, my father could speak with one other person ...

(Exhibit)

It was evident that people embraced culture-specific sessions when they were made available. Such experiences helped people living with dementia reconnect to their past culture and pleasant memories. These “cultural doses” also allowed family members to witness aspects of their loved ones assumed previously lost to dementia. However, it was apparent that culture-specific activities were offered sporadically and not as part of routine activities.

3.4 | Loss of English is not a loss of language

This theme highlights the impact of inadequate language support. Family members described how the lack

of communication options (non-English alternatives) not only limited their loved ones' ability to interact with fellow residents and care workers but also impacted their health and well-being, and level of care provision:

I think had he [my father]– had he been able to communicate and, you know, have engaged in communication for a bit longer, it would have had a significant effect on his well-being ...

(Hearing Transcript)

If my father had been able to effortlessly connect with staff in Arabic, the quality of his life would have been significantly better for a longer period ... people had said that they didn't think he had dementia when he spoke in Egyptian – it was just like he was a different person in the two different languages.

(Exhibit)

Similarly, a volunteer who spoke several languages reported the important role of language in providing appropriate care for older people from culturally and linguistically diverse backgrounds:

The man had dementia and had forgotten English. He had been admitted into care against his will. I speak a number of languages and found him fluent in German, French, Italian and Croatian. We were able to get him appropriate care.

(Exhibit)

It is evident from the extracts above that care providers construct a notion that equates loss of English language with an inability to communicate. Where English has been learnt as a second or additional language, it may be forgotten as dementia progresses. However, people may retain their first language and be able to communicate well if given the opportunity. It was not impaired cognition or communication, but rather the lack of consideration to make language alternatives available that significantly hindered people's ability to communicate, reduced their well-being, and negatively impacted care provision, similar to the findings of previous research.²³

3.5 | Neglecting opportunities and alternatives

The last theme identifies how limiting constructions and neglecting to provide communication alternatives

impacted care. Knowing that opportunities for communication were limited by a lack of shared language, family members often supplied facilities with customised communication support tools. However, despite availability, our evidence showed that such options were neglected by care workers:

They didn't use the culture, bicultural posters and albums that I had given them, and she had her first accident [urinary continence] ever and she felt dreadful.

(Hearing Transcript)

In addition, there were reports of care workers not using the clinical bicultural communication tools available in RAC facilities such as the bicultural pain scales resulting in unsatisfactory care and serious consequences:

I believe if the staff that night would have communicated with Mum by using a bicultural poster and the pain scale and called me as soon as she started crying instead of assuming it was one of her moments of depression, sadness or loneliness, we could have saved her. I think it is their duty of care to call a family member or an interpreter when a client is in distress and cannot explain why ...

(Hearing Transcript)

The evidence above shows that failure to use bicultural support tools (provided by family members) and clinical tools (bicultural pain scales available in RAC facilities) is perhaps reflective of a wider misunderstanding of the factors influencing language and communication retention for people living with dementia from linguistically different backgrounds and the assumption that English loss equates to cognitive deficits and loss of communication expression.

4 | DISCUSSION

We undertook a secondary qualitative analysis of publicly available evidence from the Royal Commission to identify the current experiences and concerns around dementia care for older people from culturally and linguistically diverse backgrounds. Our critical realist perspective maintained our analytic focus on identifying the fundamental constructions and assumptions in data, such as those around lack of language ability, and how such incorrect assumptions played a role in limiting the delivery and experience of culturally safe care

for residents. Our findings suggest that the need for meaningful cultural connection increases as dementia progresses. We identified that it was common for people from culturally and linguistically diverse backgrounds to revert to their language of origin; however, a lack of language support exacerbated communication challenges and reduced personal well-being. Access to culturally aligned food, music and language facilitated a connection with the culture of origin and supported well-being and care provision. Such findings highlight the importance of embedding language support and culturally oriented interventions into routine care. Australia is a country that encourages and indeed requires immigration to maintain its economy and standard of living and accepts migrants from all parts of the world. As migrants adopt Australia as their new home, it behoves Australian society to ensure the comfort and well-being of all citizens and residents at all life stages. Our findings provide some clear recommendations for what is needed to address this gap in equity in the provision of culturally safe care for older people living with dementia.

Our findings demonstrate that older people experienced culturally unsafe residential care including culturally inappropriate food, male staff attending to a female resident, and lack of language support, consistent with previous research.²⁴ Our findings also show that the losses associated with dementia were compounded by feelings of strangeness and unfamiliarity characterised by moving to another strange new world, and how this was exacerbated by culturally unsafe care which impeded quality of life and care. Moving to RAC is not an uncommon progression for people living with dementia as the complexities of care exceed what can be provided by family and informal carers.²⁵ For people from culturally and linguistically diverse backgrounds, this can mean moving from a home that has maintained and embraced a connection to their culture of origin to a place that is not only unfamiliar but also devoid of any cultural reminiscence or connection.

Care services addressing the individual and socio-cultural needs of people with dementia are important for culturally safe care.¹¹ While there are facilities dedicated to specific cultural or language groups (e.g. ethnic-specific, multicultural and clustered services),²⁶ family carers of older Australians from culturally and linguistically diverse backgrounds prefer ethno-specific or multicultural RAC services over mainstream services.^{26,27} This is because they can experience culturally appropriate food and activities and communicate in their own language. However, culture-specific facilities may not be feasible or sustainable in the long term due to Australia's changing migration patterns. An integrated system of care, where

ethnic-specific care and mainstream service work in partnership, may prove to be beneficial. Mainstream services can also ensure culture-specific care by providing culturally appropriate food and activities and employing bicultural/bilingual staff. Our findings reflect a similar aspiration for culture-specific care and the mainstream services incorporating cultural and linguistic diversity within routine person-centred dementia care.

Deterioration of English language expression and comprehension does not mean the loss of all communication abilities.⁵ We identified that this incorrect assumption resulted in missed opportunities for care when care workers failed to use bi-cultural communication support tools leading to misrecognition of clinical signs and symptoms, and substandard care. A recent literature review demonstrated that hospitals providing interpreter services for linguistically diverse people showed improved quality of communication and care.²⁸ Our findings also show that access to a care workforce or volunteers with the capacity to communicate in different languages can mean delivering more appropriate and high-quality care. However, further research is needed to explore the value of interpreter services and resources to support staff to engage in bilingual communication in the RAC setting. Inadequate access to resources to support older people from culturally and linguistically diverse backgrounds to communicate in their language of origin may reflect a deficit in our understanding of the capacity of people living with dementia from culturally and linguistically diverse backgrounds to communicate their needs.

4.1 | Study limitations

Our findings may not reflect the first-person experiences of older people from culturally and linguistically diverse backgrounds. However, through a critical realist perspective, we use the experiences of older people as retold by family members. The absence of first-person voices reflects the challenges of engaging people living with dementia in scholarly research,²⁹ which is often attributed to the limited language proficiency of this population.³⁰ The Royal Commission did not specifically solicit submissions from culturally and linguistically diverse populations¹⁴ and evidence from the Royal Commission included no direct submissions from people with dementia from culturally and linguistically diverse backgrounds despite notification in alternate languages and free interpreter services. The lack of representation highlights the importance of targeted approaches for recruiting participants, such as those seen in the more recent Australian Disability Royal Commission,³¹ which used culturally inclusive language, professionally qualified and accredited interpreters, and

the expertise of community organisations and leaders (e.g. faith-based leaders) in their engagement with culturally and linguistically diverse people living with a disability. Additionally, as this was a retrospective study, we were not able to follow up with the participants who shared their experiences with the Royal Commission.

5 | CONCLUSIONS

Australia and other countries welcoming migrants are responsible for providing equal access to quality care for the older people. This is fundamental to providing a sense of belonging, comfort and security which are basic tenets of person-centred care. The current provision of culturally safe care for older people living with dementia from culturally and linguistically diverse backgrounds relies on regulating bodies, aged care providers and those engaged in direct care provision embracing the various ways that diverse cultural and language opportunities can be embedded in care. Resources including interpreters, bilingual/bicultural staff and information translation, may improve the quality of care; however, these solutions may rest on other factors such as staff recruitment and increased cost of care. To ensure the needs of an increasingly diverse and older population are known and met, future research must seek alternative recruitment and data collection strategies to achieve greater participant representation.

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CONFLICT OF INTEREST STATEMENT

No conflicts of interest declared.

DATA AVAILABILITY STATEMENT

Data used for this study are publicly available from the Royal Commission into Aged Care Quality and Safety website <https://agedcare.royalcommission.gov.au/>.

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