ARTICLE



Elders' perspectives and priorities for ageing well in a remote Aboriginal community

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Abstract

Aboriginal Elders in Australia are recognised as having an important role as community leaders and cultural knowledge holders. However, the effects of colonisation and institutional racism mean Elders also experience significant social and economic disadvantage and poor health outcomes. There has been a systemic lack of attention to the worldviews and priorities of Aboriginal people as they age. In this article, we detail the findings of a qualitative study using a localised Aboriginal Elder-informed methodology that involved interviews and focus groups with 22 Aboriginal Elders in the remote town of Walgett on what ageing well means to them. This study was undertaken as part of a long-term partnership between a unique community-controlled Elders organisation and a university. The findings illuminate the barriers and enablers to ageing well for Aboriginal people in Walgett and elsewhere, and demonstrate the value to research, policy and service delivery of listening to and learning from Elders, centring Indigenous knowledges and worldviews, and bringing a more holistic conceptualisation of wellbeing to the understanding of what it means to age well.

Keywords: ageing; Aboriginal and Torres Strait Islander people; Elders; qualitative study; wellbeing; Indigenous; remote; community-led

Introduction

Aboriginal¹ Elders² in Australia are recognised as having an important role as community leaders and cultural knowledge holders (Warburton and McLaughlin, 2007; Waugh and Mackenzie, 2011; Coombes *et al.*, 2018; Quayle and Sonn, 2019; Busija *et al.*, 2020; Gibson *et al.*, 2020; Eades *et al.*, 2022), despite the ongoing impacts of colonisation and systemic racism. Dispossession and assimilationist government

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policy have enabled deeply harmful practices, including the widespread forcible removal of generations of Aboriginal children from their families into church-and government-run institutions and non-Aboriginal families, which have had a devastating intergenerational legacy on cultural, community and family relationships and traditions (Human Rights and Equal Opportunity Commission, 1997). Older Aboriginal people experience significant health, social and economic inequities compared with older non-Aboriginal people (Australian Institute of Health and Welfare, 2021; Clapham and Duncan, 2017; Coombes *et al.*, 2018; Busija *et al.*, 2020; Gibson *et al.*, 2020; Eades *et al.*, 2022; Healing Foundation, 2021).

Systemic racism against older Aboriginal people remains widespread, including in the aged care system (Warburton and McLaughlin, 2007; Coombes et al., 2018; Quayle and Sonn, 2019; Sivertsen et al., 2019; Temple et al., 2019; Cox et al., 2020; Gibson et al., 2020). The failure to provide culturally safe care for Aboriginal and Torres Strait Islander people as they age was identified as a systemic and growing problem in the recent report of the Australian Royal Commission into Aged Care Quality and Safety (2021: 237-238). Although the life expectancy for Aboriginal and Torres Strait Islander people remains approximately 10 years lower than for non-Indigenous Australians, the number of older Aboriginal and Torres Strait Islander people in Australia is projected to double by 2026 (Australian Institute of Health and Welfare, 2020). The Royal Commission report provided overarching recommendations around reforms to aged care, including that there should be active partnership with Aboriginal and Torres Strait Islander people through consultation, co-design, building cultural expertise and regional relationships, noting that there are significant opportunities for integrated, flexible and innovative aged care services that prioritise the wellbeing of older Aboriginal and Torres Strait Islander people (Australian Royal Commission into Aged Care Quality and Safety 2021: 266). Research and advocacy has made the strong case that any such policy reform must centre the perspectives and priorities of Aboriginal and Torres Strait Islander people and community-controlled organisations to be effective, and to shift from focusing on deficit-oriented and non-Indigenous paradigms towards Indigenous knowledges and community strengths (Coalition of Aboriginal Peak Organisations, 2020; Temple et al., 2020; Wettasinghe et al., 2020).

This is not just a matter for governments in Australia. The requirement to take effective and specific measures to address the injustices experienced by Indigenous people as a result of colonisation is set out in the United Nations Declaration on the Rights of Indigenous Peoples, with Article 21(2) noting that particular attention should be paid to the 'rights and special needs of Indigenous elders, women, youth, children and persons with disabilities' (UN General Assembly, 2007). While the status of Elders and their traditional roles differ across cultures (Braun et al., 2014; Eades et al., 2022), there are commonalities amongst Indigenous peoples across the world connected to the impact of colonisation and systemic racism and their distinct cultural identities and experiences. Mainstream models of 'successful ageing', 'active ageing' and 'healthy ageing' premised on being 'positive', 'productive' or 'healthy' have been critiqued for assumptions of individual choice and agency (Neville et al., 2020: 2) and as not resonating with or even causing harm to older Indigenous people who have experienced systemic marginalisation

and disadvantage (Ranzijn, 2010: 717; Holstein and Minkler quoted in Braun *et al.*, 2014: 123; Yashadhana *et al.*, 2022).

Research with Indigenous Elders internationally has highlighted a conceptualisation and experience of ageing that is holistic, cyclical and collective, with physical, mental, emotional and spiritual dimensions, and where playing an active role in passing on knowledge and wisdom to younger generations is of central importance (Jervis, 2010; Thompson et al., 2013; Wexler, 2014; Baskin and Davey, 2015). Culture, self-determination and Elders' knowledge were described as central to Elders' capacity and ability in ageing in a New Zealand study, along with value in Elders supporting other Elders during transitions in later life (Simpson et al., 2020). Eldership was conceptualised in terms of emotional wellbeing, community engagement, spirituality, physical health and wisdom gained through life experiences by Elders in south-west Alaska (Lewis, 2011). Research in Australia has demonstrated the importance older Aboriginal people place on holistic approaches to ageing, with their priorities surrounding ageing having a strong focus on community, cultural knowledge, Country³ and the sociocultural aspects of their roles as Elders (Yashadhana et al., 2022). These Indigenous concepts of ageing suggest differing values and priorities to those outlined in mainstream ageing frameworks (Waugh and Mackenzie, 2011; Dune et al., 2018; Quayle and Sonn, 2019). In contrast to mainstream ageing paradigms, 'ageing well' has been proposed as more inclusive of collectivist cultural approaches to ageing, since it enables older people to define for themselves what ageing well means to them and therefore what they need in order to age well (Ranzijn, 2010: 721-722). The ageing well scholarship has informed the approach of this research.

Led by a community-controlled organisation, the Dharriwaa Elders Group (DEG), the study reported on in this article drew on a localised Aboriginal Elder-informed methodology that involved focus groups and interviews with 22 Aboriginal Elders in the remote north-west New South Wales (NSW) town of Walgett. This study was undertaken as part of a long-term partnership between a community-controlled Elders organisation and a university, and the authors of this article include an Aboriginal Elder and staff of both organisations. The purpose of the study was to better understand what it means to age well from the perspective of Aboriginal Elders with the aim of improving resources and services to align with their needs and priorities. The research questions were:

- What does ageing well mean to older Aboriginal people in Walgett, and what are their priorities as they age?
- What are the barriers and enablers of ageing well in Walgett, including the role of the DEG?
- What future initiatives could support Aboriginal people to age well in Walgett?

In this article, we describe: the context in which this study was undertaken; its research methodology; our findings analysed into five themes; the implications of those findings; and conclude with our reflections and recommendations for research, policy and service delivery.

Context

This study was undertaken in Walgett, Australia, a remote town in far north-west NSW. Walgett's population, including the nearby Aboriginal villages of Gingie and Namoi, was recorded to be around 2,500 people in the most recent national census (Australian Bureau of Statistics, 2018). Aboriginal people from more than three different language groups live in Walgett and make up the majority of the town's population: Gamilaraay, Yuwaalaraay and Ngayiimbaa. The Walgett Aboriginal community has significant strengths founded in its cultural beliefs, connections to Country, family and community loyalty, and strong local community-controlled organisations (Walden, 2016; DEG, 2020). Walgett has a long history of Aboriginal people engaged in political activism, advocacy and research. Walgett has also been measured consistently as one of the most disadvantaged areas in Australia (Vinson and Rawsthorne, 2015; Australian Bureau of Statistics, 2018). Aboriginal people in Walgett experience particularly high rates of intergenerational poverty, overcrowded and inadequate housing, poor physical and mental health, high rates of disability, high costs of living, low employment participation and poor educational outcomes (Australian Bureau of Statistics, 2018). Government contracting arrangements and service delivery models are not designed for small remote communities such as Walgett, in particular culturally safe services for Aboriginal people (Walden, 2016).

The DEG is an association of Aboriginal Elders that provides leadership on a range of community development and cultural engagement activities in Walgett, established in 2000 in response to local community priorities and aspirations (DEG, 2020). Working closely with the Walgett Aboriginal Medical Service, DEG has also been actively engaged in advocacy and research over the past two decades (Walden, 2016; DEG, 2020). After collaboration on a research study investigating the criminalisation and incarceration of Aboriginal people with mental health disorders and cognitive disability, the DEG invited the University of New South Wales (UNSW) to work with them to address their long-term vision for positive social change in their community in what has become the 'Yuwaya Ngarra-li' (YN) partnership (McCausland et al, 2021). From the outset, there was a shared understanding between DEG and UNSW that any collaboration had to move beyond individual studies or programmes to focusing on long-term solutions to the causes of disadvantage and discrimination experienced by Aboriginal people in Walgett.

In its emphasis on effecting systemic change, the YN partnership is committed to contributing to a broader evidence base that could benefit other Aboriginal communities and improve research and policy. It aims to improve the environment, life pathways and wellbeing of Aboriginal people living in Walgett through collaboration on evidence-based initiatives, research, and building local community capabilities and control. YN builds on decades of strong advocacy, community development and participatory research which has focused on addressing structural injustices and inequity through centring Indigenous knowledges, worldviews and rights (Robinson, 2020). The DEG and UNSW researchers developed the YN Research Protocol that sets out the context, principles and processes for research undertaken as part of the partnership (McCausland, 2019). The protocol was developed against the backdrop of research as something that is still regularly *done to*

rather than *in collaboration with or controlled by* Indigenous peoples (Smith, 1999; NSW Aboriginal Health and Medical Research Council, 2020). It acknowledges that such research is inherently political and connected to past and current policies, processes and practices (McCausland, 2019).

The Elders Council and staff of the DEG have for many years discussed the need for locally led research around how to improve respect, services and support for Elders, along with documentation of DEG's unique model of an Aboriginal community-controlled Elders organisation. Fresh momentum came after interest from the Australian Royal Commission into Aged Care Quality and Safety into DEG's work, while at the same time new funding arrangements were being proposed by the Australian Government that would undermine the model of culturally led support that the DEG provides. DEG requested UNSW undertake this research through its partnership, and UNSW collaborators built a team of investigators and secured funds (Andersen et al, 2019).

Research methodology

This study builds on the growing body of research led by and involving collaboration with Indigenous Elders across the United States of America, Canada, New Zealand and Australia. In attempting to redress the power imbalance and privileging of researcher priorities and timelines, Braun *et al.* (2014: 122) note that researchers have been increasingly using the more transformative and relational approaches of participatory action research and community-based participatory research to engage First Nations Elders in research that can have tangible benefit to communities, including improving wellbeing (Kovach quoted in Braun *et al.*, 2014: 122). These approaches aim to improve the lives of those engaged in the research and allow Indigenous Elders to be 'navigators of their own inquiry', creating space for Elders to tell their stories and challenge non-Indigenous researchers to acknowledge values and worldviews different to their own (Braun *et al.*, 2014: 124). Braun *et al.* (2014: 125) note that future research in this growing field of Indigenous gerontology requires partnership with Indigenous Elders, families and communities.

This study's methodology was informed by participatory (Cochran et al., 2008; Wallerstein et al., 2018), critical (Delgado, 1995; Bernard and Scharf, 2007) and decolonising (Denzin et al., 2008; Braun et al., 2014) research frameworks that centre Indigenous perspectives, worldviews, leadership and control of research (Smith, 1999; Bagele, 2012), as well as localised community and culturally specific knowledge and protocols led by the DEG. Two researchers had experience and training in 'yarning' as a specific Indigenous research method (Bessarab and Ng'andu, 2010). Yarning generally refers to informal, relaxed conversations between researchers and participants that are flexible yet purposeful, with participants sharing their stories and lived experiences relevant to the study topic. This research method entails establishing a human connection and deep, respectful listening, with the researcher paying close attention to participants' narratives as they choose to tell them. The DEG's research method resonates with this theorisation but has specific elements developed and refined over many years with Elders and others in the Walgett Aboriginal community. It is regularly used by DEG to progress and document Elders' thinking or positions regarding an issue, e.g. in developing policy statements. It is also used to

understand and gather local evidence and to develop plans and projects for the work of the organisation. Core to this is the trust that has developed through deep and respectful listening, learning, reflection and collaboration with Elders and others guided by cultural and community protocols, and a collective vision for positive social change determined by community priorities. The DEG's research method is described in more detail in the Data Gathering section below.

Participants

Elders in Walgett were approached by DEG staff or other Elders and invited to participate in one-to-one interviews and focus groups. Over the course of several days, two focus groups with 22 Elders and six in-depth interviews with individual Elders (three female and three male) took place. Vouchers were provided to those who participated as a means of recognition of the valuable contribution of time and experience. A series of interviews were also undertaken with Aboriginal and non-Aboriginal service providers in Walgett that are not reported in this article as it focuses specifically on the voices, perspectives and priorities of Elders themselves.

Data gathering

The two focus groups were facilitated by WS, a non-Indigenous woman who has worked with the DEG since its inception more than 20 years ago. WS has a deep understanding of cultural and community protocols and close relationship of trust with the Elders while also positioned outside that experience. After taking time to ensure that all participants were willingly engaged and supportive of the aims of the session, ensuring informed consent including for recording, the facilitator asked a series of questions relevant to the knowledge, lived experience, status, family and Country relationships of individuals. The open-ended questions built on previous answers, often drilling down for clarity; examples were given to illustrate parts of the question that relate to shared experiences, including stories of something that happened to Elders in the history of the organisation or in experiences shared by those present. In keeping with the core principle of 'do no harm' that DEG brings to all its work, each participant was given respectful space and time to respond, and never asked a question in a way that could be confronting or shaming to consider or answer; individual traumas are recognised and steered away from by the facilitator. Breaks and refreshments were provided. When the facilitator sensed that participants' engagement was concluding, a recap was given of key responses and reflections so that the facilitator could check they understood correctly and could write up the discussion appropriately. This then informed subsequent sessions and documentation that were brought back to Elders for reflection and endorsement. A further planned collective data analysis session amongst groups of Elders was not able to take place due to COVID-related restrictions on gathering.

The in-depth interviews with six Elders were undertaken by members of the research team with expertise in qualitative research who had been working closely with the DEG for many years and built up relationships of trust and connection: one Aboriginal researcher (PM) and one non-Aboriginal researcher (RM) from the YN partnership. Other researchers who were known to and trusted by Elders

(including MA) assisted with recording, gathering consent, note taking and transcribing the focus groups and interviews. The transcripts were then comprehensively checked with Elders, who were asked to confirm if the transcripts accurately reflected their views and if they wished to add or change anything. Elders were invited to participate further in data analysis and provide any further feedback about outputs or outcomes they wished to see from the study, and provided with an anticipated format and timeline for reporting back.

The DEG determining the protocols and approach to all stages of the research, including data gathering, aligns with international standards and scholarship regarding ethical practice for research with Indigenous Elders and communities generally, including by Braun *et al.* (2014), Bagele (2012), Denzin *et al.* (2008) and Smith (1999). This method of data gathering also means the findings are robust and useful given the purpose of the study: to better understand the priorities and needs of older Aboriginal people in Walgett in order to improve resources and services in Walgett and other communities.

Data analysis

The objective of the data analysis was to produce a descriptive set of themes encapsulating what Elders said it means for them and other older Aboriginal people in Walgett to age well. The study used inductive data analysis, taking a grounded theory approach (Charmaz, 2014) to develop themes from the data rather than applying an existing coding framework. Concurrently, there was an iterative process of data interpretation in collaboration with Elders who had participated in interviews. One Elder (VR) nominated to join the investigator team as part of the data analysis process. The data analysis was completed in four stages. Stage 1 involved two researchers, one who was involved in the research yarns (MA) and one who was not (SKJ), separately coding a deidentified sample of the Elders' transcripts. Codes were systematically compared and discussed to identify points of similarity and difference between the two researcher's codes. In stage 2, codes were discussed with a third researcher who had conducted the interviews (RM), to check that they aligned with her interpretation of the data. Once codes were agreed upon, SKJ continued coding, using NVivo 12 software as a data management tool. MA, SKJ and RM also created a document containing a definition for each code, for sharing with the DEG and wider investigator team. Stage 3 consisted of SKJ and MA developing a coding tree for discussion with the full investigator team, grouping the codes into categories and sub-categories. There was agreement amongst investigators that the coding accurately and appropriately captured the data. In Stage 4, SKJ identified themes in collaboration with MA and RM. A draft analysis document was distributed to the investigator team for discussion and feedback. Revisions were made to the document based on the investigator team's feedback, including detailed input from one Elder (VR). This led to the preparation of a Community Report for the DEG and the themes reported in this article.

Community reporting

As part of the YN Research Protocol, all studies undertaken as part of the partnership involve a process of reporting back to the community. The DEG Elders Council and other Elders interviewed had identified outputs they wished to see from the study, including a community-oriented report setting out findings and recommendations that could be used for advocacy and funding proposals. This report was drafted and provided to the Elders Council for their review and feedback to ensure it appropriately captured the methodology and analysis of the study and met community expectations and priorities. Other outputs from the study were transcripts of interviews designed and provided to Elders for them to keep and share with their families if they wished, and posters containing key quotes for display in the Elders Centre.

Ethics

Ethics approval for the study was obtained from the NSW Aboriginal Health and Medical Research Council and UNSW Human Research Ethics Committee.

Limitations of the methodology

Given the study's methodology, recruitment to participate in interviews and focus groups was done via DEG Elders and staff. Although they sought to invite a range of older Aboriginal people in Walgett to participate in the study, including those not actively engaged in DEG activities, there are likely to be perspectives and priorities amongst some older Aboriginal people in Walgett not captured in this study. Due to COVID-related restrictions on gathering, feedback from Elders on the thematic analysis and findings was more individualised than initially planned.

Findings

There were five major themes identified from the analysis of interviews and focus groups with Elders:

- Elders fulfilling their roles as the 'wellspring' for younger people is important.
- The ongoing impacts of colonisation impacts on Elders ageing well.
- Independence and choice are valued but constrained.
- The DEG supports Elders' holistic concept of wellbeing.
- Elders want a culturally safe model of aged care, not parity with non-Indigenous older people.

Elders fulfilling their roles as the 'wellspring' for younger people is important

Elders talked about ageing well as connected to being respected and continuing your role as the 'wellspring' for younger people, as one Elder described it. Elders are knowledge keepers for the younger generations and protectors of cultural heritage. This involves passing down knowledge and stories, leadership, care-giving, and safeguarding family, community and intergenerational wellbeing. As one Elder explained:

I go back to talking about our stories, and storylines, and telling those stories ... It's Aboriginal culture – it's an oral system of educating people and giving people

information. It's part and parcel of Aboriginal life, that's the whole gamut: you know your stories, you know where you come from.

For some Elders who have worked away from Walgett in various careers including in government, this means a kind of 'active retirement', bringing back knowledge and experience to benefit community and build community capacity. Those Elders spoke about returning to Country (to Walgett) for their later years to continue their role in community and provide leadership and a legacy for the next generation. One Elder said: 'Everyone comes back', and another: 'Once you have an education, you take it back to your community'. Elders spoke about the strength of the local community, the friendliness and wellbeing that comes from living in a small town where you know people and stop to have a yarn, and younger people say hello to you in the street. One interviewee said: 'I'm surprised how many young kids there are in the street that say "Hello Aunt". It's lovely.' This intergenerational connection was highly valued by Elders.

Elders spoke strongly about the importance of contributing to the wellbeing, education and knowledge of younger generations in what it means for them to age well. They shared concerns at not being able to pass down knowledge due to physical, cognitive or mental health issues. One Elder talked about how critical this is in the following terms:

I think it's important, very important, that they're well to continue their role. They're caretakers, they're the keepers of the family. It's a big role and once you're older and you've got a few chronic diseases under your belt, you do worry that you won't be able to fulfil that role, of looking after family and caring for your community.

Elders spoke about how roles differ for women and men. The special role of female Elders was talked about, including caring for children and passing down knowledge and skills for survival:

My grandmother and I used to go fishing a lot, and she would never go fishing without coming home with a feed of fish [fish caught for a family meal]. One day down at [local river bend], we had a look at the shrimp can and there were three little water pups⁴ in there. 'We should take these home', I said, and she said 'no, the big water dog will get you!', so I put them back.

The spirit dog Mirriwuula featured in yarns of Elders who lived at Namoi Village; Aboriginal people growing up there were told it lived in Mirrigana, a deep waterhole in the Namoi River beside the Village. Fishing was a regular and important food-gathering pastime for the whole community, and an opportunity for Elders to pass down important stories about culture and Country.

Elders also talked about sharing knowledge of the impact of past assimilationist policy and the survival of parents and grandparents who were part of the Stolen Generations and came back to Walgett when they were adults. They reflected on their experiences of overt racism and discrimination, *e.g.* segregated schools and being told they would 'amount to nothing', and also of overcoming barriers, getting

a job and respected roles despite this. Elders spoke about the impact such treatment had had on their social and emotional wellbeing as children and how this motivated them to support the younger generation and address ongoing racism and discrimination within the education system. They described how far things had come since the days when they could not lawfully leave the government-run missions and enter Walgett town without permission from government administrators, but also how much work there still was to be done to address the systemic racism experienced by Aboriginal people.

The ongoing impacts of colonisation on Elders ageing well

Elders explained that dispossession and now climate change, drought, water insecurity and the river drying up are ongoing harms to the health and wellbeing of the community. The river is at the centre of cultural stories and knowledge of Gamilaraay people. The river has also provided a vital way for Aboriginal families in Walgett to survive under discriminatory colonial government policy. Elders shared their childhood experiences of poverty, serious childhood illness, siblings dying due to lack of health care and families needing to move around to find work. In this context, connection to Country and being able to live off the land was, and continues to be, important to survival:

Well I used to always say that if we had a healthy river, we would have healthy people. It makes life a hell of a lot easier. When I was a youngster we would go fishing and that was how we survived when the men were put off at the stations and they had no work. It was a hard slog but we managed.

As reflected in the quote below, the impacts of colonisation on connection to Country have also disrupted kinship systems in Aboriginal law, defining roles and responsibilities. This was described as a deep harm to the cultural wellbeing of Elders and the whole community:

Well when I think about ageing and culture I think one of the big things that is on people's minds, especially elderly Aboriginal people, is the fact that the rivers have dried up, and how that affects culture to me, it's like another wave of destruction of our culture. It first happened when they came and took the Country and settled the land. They took all our cultural heritage away from us. It caused lots of problems, particularly with Aboriginal kinship systems.

Elders described disruption of family relationships, cultural traditions and connection to Country as having difficult implications for Aboriginal people as they age. For example, one Elder described a loss of traditional caring practices and more reliance on mainstream aged care services in a way that did not happen for previous generations:

Yeah see, you never had age packages, you never had all that stuff, it was just what families were able to provide themselves and do. And it tells you that somewhere along the way we got too dependent on these other things, rather than love and care and kindness and that stuff.

The ongoing impacts of colonisation were also described in relation to Elders' experiences of institutional racism within multiple local mainstream services, which compounds problems with service access relating to Walgett's remote location. For example, one Elder described the hospital in Walgett establishing a committee to determine the new layout of the hospital, but the advice of Elders was ignored. This resulted in the new layout being a barrier for older community members with low mobility. Other hospital accessibility issues include unreliable patient transport, lack of specialists locally requiring Elders to travel out of town for a day or longer, lack of diagnostic equipment, and lack of dialysis chairs for people with diabetes, requiring some people to move permanently out of town. Some Elders are unable to age on Country in Walgett because of the lack of health professionals, as illustrated by this quote from an Elder who had to move away from Walgett as he and his wife were not able to access health specialists:

She got sick up there because there were no doctors, the doctors couldn't look after what she had wrong with her, respiratory problems and all that, so they put her back into Sydney hospitals and she was down here [in Sydney] for 8 months. She ended up dying. So I went back up to Walgett and ... I started to get the same problem, and there was no doctors there – sometimes there was a doctor and sometimes there wasn't. So I packed up and came back to Sydney where there were doctors.

Many health professionals are not based in the community but fly in and out which can create a problematic lack of continuity of care for people with complex chronic health problems, which disproportionately affects Aboriginal people. At the same time, the destruction of the physical environment has interfered with the availability of bush medicine that many Elders were raised with.

Culturally safe palliative care for older Aboriginal people was specifically mentioned as a service gap that needs development in consultation with Aboriginal families:

It's probably quite an easy thing to get done, because if you speak to the family they will have a fair bit of knowledge about dying. But nobody speaks to the family about a palliative care plan, in a cultural way.

Independence and choice are valued but constrained

Maintaining independence and having the resources to do this (e.g. housing and financial security) was seen as important to ageing well for many of the Elders interviewed, however, this was constrained for most. Independence was described as continuing to do the things that make you happy and being as self-sufficient as possible. Elders talked about ageing well as ageing at home and being able to access social activities. Elders said that for older Aboriginal people who need support and assistance to remain comfortably in their homes, access to care and support from people they trust is vital, either through family and community networks or services. Elders spoke about support from family and friends, having a choice of culturally safe aged care services and access to transport as important things to help

to maintain independence. However, many Elders expressed concerns that this would not be available to them, as one articulated:

As I get older, I wouldn't be able to move away, drive around. I worry about being at home, homebound, I wouldn't be able to get around, lose my independence. I want to do things myself, not ask other people.

Access to transport was considered particularly important to ageing well given Walgett's remote location but also a major systemic problem. Many older Aboriginal people do not have their own transport and are reliant on services or others in the community. There is no taxi service. Not having your own car was described as a barrier to important things such as seeing family, going to funerals and accessing health care. Elders spoke about DEG transport as very important to overcoming these barriers and helping Elders with shopping and getting to appointments. Elders identified the need for more community transport, especially on the weekend:

With the transport services, if we had a bus – if you want to go out to the club, or for a party or go for a night out, or go for a meal, you have to think about somebody to drive. Not a bus or anything, they don't offer that. Even the clubs, they don't offer that.

Many Elders spoke about their strong preference to live somewhere quiet, secure and safe in order to age well and comfortably, and yet there is a community-wide issue of a lack of housing which affects people's capacity to age with independence and choice. This is an issue of both quantity and quality; there is a shortage of affordable housing and existing homes are overcrowded and in poor physical condition. Poorly built housing not suited to the local climate means very high energy costs associated with very high temperatures in summer and very cold conditions in winter. Policies and practices of housing providers were described as additional barriers. Elders described making requests to social housing providers for a transfer to a different house that would enable family to move in and take care of them, but these requests not being met. Under-resourcing of appropriate infrastructure and services in a remote area like Walgett compounds the institutional racism and lack of cultural safety⁵ experienced by Aboriginal people.

There is also a lack of appropriate residential aged care accommodation in Walgett. Given this, access to high-quality services to support ageing at home was considered particularly important. Elders also prefer to age at home, identifying that services need to be culturally safe and provide access to staged care, depending on their level of need. Some Elders suggested they would benefit from culturally safe low-level residential respite care to take a break from living alone, but currently this is not available.

The DEG supports Elders' holistic concept of wellbeing

Wellbeing was conceptualised holistically by Elders as having social, mental, physical, cultural, political, family and community dimensions. Elders described how their personal journey and wellbeing across the lifespan connect to their wellbeing now, reflecting on past and current experiences to describe what it means to age

well. Staying physically and mentally active were mentioned, however, these were inextricably linked to collective and culturally oriented dimensions of ageing well. The DEG was seen as a vital space that responds to and nurtures all the dimensions of wellbeing for them as ageing Aboriginal people.

Many examples were shared about important aspects of social wellbeing, including meeting with other Elders, helping others with practical support, going to social activities in the community and coming into the DEG. These were seen as critical for dealing with loneliness and social isolation, which Elders explained are made worse by grief and loss of loved ones. Elders spoke about the benefits of socialising with other Elders, as there is mutual understanding, respect, laughter, and shared interests and stories. The DEG was identified as an important place for social and cultural connection and support, as these Elders said:

People tell jokes, you come in here and have a yarn about different things. Makes you feel good when you come in here and talk to people.

It's a very lovable place. You can have good time here, always bump into people. I know a lot of people. Good to go somewhere, meet people.

Well, I think the Elders Group is important, that we have this organisation here, we've got people together of the same age group, the same mindset. You see it when older people are just around young people, they aren't exercising their minds as much because they don't know what they're talking about. The older person doesn't understand, and they're just left there wondering. So if you've got similar age, similar thinking, they can have a conversation.

Keeping mentally active was seen as important: having a good conversation, keeping your mind occupied, playing cards, and socialising with other Elders and family. As this Elder said:

To keep active – not just physically active, but mentally active, it's very important. Old people can go through loneliness, prisoner in their homes. They get stuck there and you forget them.

Staying physically active was seen as important, linked to getting out and about including regular visits to the DEG centre, caring for grandchildren, having a social life, continuing to walk or using a scooter to enable independence. Continuing hobbies, gardening and doing your own shopping were also mentioned as important by some Elders. Diet, exercise and good management of health/chronic conditions were also raised as critical for staying healthy. The local Aboriginal Medical Service coming into the DEG to do regular health checks with Elders was mentioned as an important element to this.

Elders also spoke about the importance of staying engaged politically and contributing their knowledge and skills for their own wellbeing as well as that of their families and community. Examples of this included advocating for change for their community, passing down knowledge, spending time at the DEG centre, and contributing to DEG's policy and advocacy work in protecting cultural heritage:

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There's nowhere else you can get a dose of culture every day. The Elders provide that avenue for our culture and cultural heritage.

The valuable leadership provided by community-controlled organisations, and being politically engaged and staying active in the community through an organisation like the DEG was seen as a strong contributor to wellbeing for a number of Elders.

From an Elders' business perspective, the DEG is a place for Elders to lead. It is a place for intellectual stimulation and leadership, contributing to policy and political work. The DEG has an important role in confirmation of Aboriginal identity of people with family connections to Walgett, including those forcibly removed from their families and Country by government policy. The DEG plays a vital advocacy role in the community, addressing issues of systemic discrimination, marginalisation and racism, and areas of priority to the community such as food and water security. Elders are actively involved in the DEG and other committees and working groups to support the wellbeing of young people through school and health programmes. Through the YN partnership with UNSW, the DEG is working towards a long-term vision of positive social change in Walgett, including greater Aboriginal community control of services and decision-making.

Elders want a culturally safe model of aged care, not parity with non-Indigenous older people

When describing what could enable them to age well, Elders talked about the importance of culturally safe services and support, and regularly gave examples of the DEG or the local Aboriginal Medical Service to illustrate what that looked like. Elders interviewed felt strongly that mainstream models and the treatment of older non-Aboriginal people was not useful in the context of identifying what aged care should look like. Participants believed that the government and many non-Aboriginal families do not value their older people; that they are treated very poorly by aged care service providers and members of their own family. Elders saw no imperative for older Aboriginal people to achieve parity in the standard of care received by non-Aboriginal people. As these Elders said:

See, this is a problem, a big problem. They've had the Royal Commission, and the report, but the problem as I see it, it's a big one. They did do some investigation of ageing Aboriginal people, but how do they fully know what to look at? Come and talk to us. What I mean by this is closing the gap [the Australian Government framework for addressing the disparity between outcomes for Indigenous and non-Indigenous people] well, there is no such thing for ageing ... Because non-Aboriginal people, we can see they're getting a bad deal. So how can we compare our care, when there isn't anything like that? Education, we can catch up with other people. Life expectancy, that's another target. But nothing is done around healthy ageing for Aboriginal people, there isn't a target. They've already stuffed their own people up.

As a result, losing independence and becoming dependent on the aged care system was described as a big worry or fear for older Aboriginal people. Worries and fears

were connected to the lack of culturally safe aged care services and reports in the news about abuse of older people in the aged care system. Elders are worried that non-Aboriginal service providers do not understand Aboriginal culture and the needs of older Aboriginal people:

I think there's always been a difference in the aged care needs of Aboriginal people. We're in a system, an English system, and I think our care needs are different. Not that we need to be in a building with four walls and just sit there. They don't understand the Aboriginal way because they never learn it, we learnt their way.

Elders talked passionately about culturally safe care meaning being truly cared for, not just having your needs met. The traditional way of caring was described as based on being loved, valued, respected and safe. A culturally safe model of aged care would integrate these components or ethics of care into practice.

Elders highlighted the need to acknowledge the intergenerational trauma of institutionalisation, especially for survivors of the Stolen Generations who had grown up in institutions. Elders described a lack of acknowledgement within aged care services of the impact of entrenched racism and discrimination experienced by Aboriginal families, and Elders' concerns around agencies coming into their home because of previous experiences of racism and state violence in this context. If residential aged care is the only option, then Elders want access to culturally safe residential aged care that allows for family contact and safe freedom of movement. Some Elders likened current residential aged care facilities to prison and proposed that better models of housing for Aboriginal people as they age are urgently needed:

Where they can be looked after and have family with them, but you know, don't lock the doors. I mean, maybe a front door at night or something like that, but people can still move around.

A number of Elders suggested that family carers need to be supported and resourced to provide care for their Elders. Elders are understandably cautious about who they let into their homes from formal services and explained that informal care was better and readily available in the Walgett community:

A lot of other people come and help you, more so than those who have been designated to do it. Sometimes family, neighbours and friends.

Others raised the need for formal aged care provision to be properly resourced to attract and retain people who want to specialise in aged care for Aboriginal people. One Elder reflected:

I sometimes think having the right staff there, whether you are Aboriginal or non-Aboriginal, as long as they're caring and empathetic. I think if you just want to do your job then it's not right for you, aged care is specialised. You need some connection, not just part of your job.

Culturally safe care as you age was described in various ways by interviewees but primarily as ideally being provided by Aboriginal people:

Aboriginal people know their people, they're not racist towards their people. Racism is a big thing and it does rear its head in ageing. [Aboriginal people] understand the way a person speaks, what they might mean, as opposed to say, a non-Aboriginal person, they wouldn't understand it. Aboriginal people are closer to the language, to the extended family. They'd be good, to be trained up in aged care.

The need for specialist training of an Aboriginal health workforce specialising in aged care was raised by a number of Elders.

Discussion

Aboriginal Elders in Australia are recognised as having an important role as community leaders and cultural knowledge holders. However, the effects of colonisation and institutional racism mean Elders also experience significant social and economic disadvantage and poor health outcomes. There has been a systemic lack of attention to the worldviews and priorities of Aboriginal people as they age. The purpose of this study was to better understand the priorities and needs of older Aboriginal people in Walgett around ageing well with the aim of improving resources and services. The themes identified from interviews and focus groups were: Elders fulfilling their roles as the 'wellspring' for younger people is important; the ongoing impacts of colonisation impacts on Elders ageing well; independence and choice are valued but constrained; the DEG supports Elders' holistic concept of wellbeing; and Elders want a culturally safe model of aged care, not parity with non-Indigenous older people. Each theme is discussed further below, along with the implications of the findings for research, theory, policy and practice.

The theme of Elders fulfilling their roles as the 'wellspring' for younger people was identified as important in terms of Elders' own health and wellbeing, but also important on a community and cultural level. Elders are responsible for passing down knowledge, leadership, care-giving, and safeguarding family, community and intergenerational wellbeing, all of which are seen as vital to Aboriginal people in Walgett surviving and thriving. Colonisation has eroded some cultural practices and relationships, and while this is associated with grief and loss for Elders, it does not mean they see their responsibilities as diminished in light of this. Many Elders have returned to Country after living away from Walgett to contribute knowledge they hold from their grandparents and other Elders, including about the history of fighting for rights and recognition for Aboriginal people. This responsibility is not viewed as a burden but as bringing purpose and connection - to their culture, their ancestors, their community and their descendants - as they age. There are also broader societal and systemic benefits to Elders taking up leadership roles and advocating for an alternative worldview informed by cultural traditions and practices that respect the knowledge and wisdom of older people, in contrast to more individualistic mainstream worldview and policy paradigms.

This theme around the roles and priorities of Elders resonates with past research in which Indigenous people have described ageing for Indigenous peoples in holistic, cyclical and collective terms; as having physical, mental and cultural dimensions; and as actively passing on knowledge and wisdom to younger generations (Jervis, 2010; Thompson et al., 2013; Baskin and Davey, 2015). Although this study is focused on Elders in one remote community in Australia, the findings echo those of research internationally around Indigenous peoples' conceptualisation of wellbeing, including a strong focus on community, cultural knowledge and Country (Yashadhana et al., 2022). This study extends existing research that indicates that Indigenous cultural identity can lead to discrimination in the context of health and aged care systems, yet it is also a protective factor in the resilience it can bring Elders in the face of such discrimination (Yashadhana et al., 2022). There are certain resonances in how Walgett Elders described ageing well with mainstream ageing concepts such as the importance of autonomy, choice, and staying mentally and physically active. However, this, like other qualitative studies with Indigenous Elders cited above, extends that conceptualisation to more collective imperatives for staying healthy and active. This study makes a distinct and innovative contribution in centring the specific experience of Elders in the remote community of Walgett, some of whom grew up on and continue to live on the lands of their ancestors and some of whom are survivors of the Stolen Generations who have reconnected with community, culture and Country. These are new voices in research regarding what it means to age well.

The ongoing impacts of colonisation on Elders ageing well, explicated in the second theme, are evident in the poverty, disadvantage and racism experienced by Elders. Few Aboriginal people own their own homes or are financially secure as they age, and some do not have family to care for them as would have been the norm in the past; as a result they are dependent on government services which are not designed for their needs or worldviews and live in social housing which is overcrowded and poorly built. Walgett's remoteness and limited locally based health professionals exacerbates Elders' access to the medical care they need as they age, which for some means they cannot age on Country as they wish to. The destruction of Country and the poor state of local rivers in particular has a devastating effect on Elders given their holistic conceptualisation of wellbeing. Colonisation and dispossession have disrupted access to cultural knowledge, local food sources and bush medicine, which also impacts on their capacity to age well.

The findings relating to this theme highlight that any policy response must not just focus on reform in aged care, but also on the health, housing and social sectors, amongst others, centred on a holistic concept of wellbeing. An effective policy approach to supporting Elders to age well needs to address the systemic disadvantage and institutional racism experienced by older Aboriginal people. Reparations for the Stolen Generations and their descendants are still being negotiated in most jurisdictions in Australia, including Elders interviewed for this study (Healing Foundation, 2021); the findings from this study indicate reparations and systemic responses could include access to funds that Elders and their families could use to secure appropriate housing and in-home support along with investing in Aboriginal community-controlled services and culturally trained staff to support Aboriginal people as they age. Better resourcing is also needed for policy and

programmes focused on the cultural, social and political dimensions of wellbeing identified in this study, such as Elders' centres and outreach that focus on language, culture and community. Indigenous knowledges also have a critically important role to play in informing policy responses to climate change. The DEG has recently established a local ranger programme with the support of the YN partnership with UNSW and funding from the Australian Government. The ranger programme employs local Aboriginal people to care for Country and rivers, learning from Elders and building evidence for a model that other Indigenous groups could implement.

The third theme around independence and choice being valued but constrained for Elders highlights that current mainstream models and theories of ageing are relevant to a certain point but largely not accessible nor appropriate for Elders due to different worldviews, socio-economic disadvantage and institutional racism. These findings support existing research about those models and theories not resonating with or even causing harm to older Indigenous people who have experienced systemic marginalisation and disadvantage (Ranzijn, 2010: 717; Holstein and Minkler quoted in Braun et al., 2014: 123; Neville et al., 2020), and about differing values and priorities to those outlined in mainstream ageing frameworks (Waugh and Mackenzie, 2011; Dune et al., 2018; Quayle and Sonn, 2019). Critiquing mainstream models and concepts does not mean that Elders do not wish to exercise individual choice and have independence as they age however, rather that policy should aim to enable Aboriginal people like non-Aboriginal people to age in the environment and context they identify as having value for them. The concept of 'ageing well' resonated with Elders interviewed for this study, adding weight to Ranzjin's (2010: 721-722) proposal that it is a paradigm more inclusive of collectivist cultural approaches to ageing, since it enables older people to define for themselves what they need in order to age well.

From a service delivery perspective, there are specific challenges associated with Walgett being a small remote community. Housing, transport and services are limited. Yet there are also significant benefits associated with enabling Elders to age on and care for Country and stay connected to extended family, as well as opportunities. Unemployment amongst Aboriginal people in Walgett is high; family and community members could be trained and employed to provide in-home support and transport for Elders, for example. Walgett is not unique in facing these challenges, and this research is already leading to possible solutions. For example, through the YN partnership, an Aboriginal architect is building on this study to develop a model of Elders housing that could be built in Walgett and other remote communities as part of their postgraduate studies. The Australian Government has also recently announced new funding for 250 Aboriginal and Torres Strait Islander staff across the country to assist older Aboriginal and Torres Strait Islander people to navigate and access aged care services that meet their physical and cultural needs, as well as the development of cultural safety guidelines to providers working with them, which will be delivered in partnership with the National Aboriginal Community Controlled Health Organisation (Wells, 2022). In announcing the funding, Assistant Minister for Indigenous Australians, Malarndirri McCarthy, said:

Lack of culturally safe care, a complex system, ongoing trauma, and social and economic disadvantages all contribute to older First Nations people accessing aged care services at a rate lower than needed. The Government is committed to delivering aged care and health services that meet the needs of our Elders and enables them to remain close to their homes and connected to their communities. (Wells, 2022: 2)

While the funding announced is not sufficient to build the workforce needed across all communities, it is a positive development.

The fourth theme about the specific leadership and vital role of the DEG as a community-controlled Elders organisation in Walgett has particular implications for research, policy and practice. The findings reflect the ways that the DEG reflects and supports the social, mental, physical, cultural, Country, family and community dimensions of wellbeing articulated by Elders. While a holistic conceptualisation of wellbeing (Lewis, 2011; Yashadhana *et al.*, 2022) and culture, self-determination and Elders' knowledge being central to Elders ageing well (*i.e.* Simpson *et al.*, 2020) have been described in other Australian and international studies, this study makes a distinct and unique contribution with regards to its documentation of the model of the DEG, a community-controlled Elders organisation. DEG is resourced to provide practical support like transport and a social space for Elders to gather. It also enables Elders' active participation in leadership, knowledge transfer, intellectual engagement and advocacy, which is leading to tangible and systemic change for their community and others.

As an Elder-led study as part of a long-term partnership between an Indigenous community-controlled organisation and a university, this research makes an innovative methodological contribution to the field of ageing research. DEG requested YN's projects include this research with the explicit aim to improve services and support in their community, and to share this knowledge with other communities. The study was grounded in relationships of trust and centred on the perspectives and priorities of Aboriginal Elders about what ageing well means to them. Researchers involved were long-term trusted collaborators, which is reflected in the richness of the data. Its methodology speaks to the recommendations of Braun *et al.* (2014: 124), based on their review of research led by and involving collaboration with Indigenous Elders. Resourcing Elders' groups drawing on the DEG model elsewhere in Australia and even for other Indigenous groups internationally could make a significant contribution to supporting other Elders to age well in their communities.

The fifth theme was powerfully illustrated by Elders: they want a culturally safe model of aged care – not parity with non-Indigenous older people. Institutional settings and palliative care were identified as particularly culturally unsafe for Elders and their families, invoking fear and distress. There have been systemic failures by governments in Australia as elsewhere to provide culturally safe care and support for Aboriginal people to enable them to age with dignity and agency, however, there is little evidence of positive models for ageing well for non-Aboriginal people. Parity in this context is not what Elders aspire to. There are great strengths in Aboriginal communities, culture and community-controlled organisations evident in the descriptions from Elders of the holistic and relational nature of wellbeing and the support that does exist in Walgett. This study provides further evidence of the widespread systemic racism against older Aboriginal people in the aged care system (Warburton and McLaughlin, 2007; Coombes *et al.*, 2018; Quayle and Sonn, 2019;

Cox et al., 2020; Gibson et al., 2020), and of the specific and urgent unmet needs for survivors of the Stolen Generations (Healing Foundation, 2021). It also contributes to the body of research and advocacy that posits that policy reform must centre the perspectives and priorities of Aboriginal and Torres Strait Islander people and community-controlled organisations to be effective, and to shift from focusing on deficit-oriented and non-Indigenous paradigms towards Indigenous knowledges and community strengths (NACCHO, 2011; Temple et al., 2020; Wettasinghe et al., 2021). Elders identified that policy frameworks that recognise, respect and resource these strengths are needed.

The Elders' perspectives in this study resonate with other research on what is required to ensure service providers provide culturally safe care for Indigenous peoples: short one-off training courses (which are regularly recommended but not yet even the norm) are insufficient. Cultural capability building amongst non-Indigenous service providers needs to be embedded and ongoing in education and training; be designed and where possible delivered by Indigenous people; focus on the impacts of colonisation, white privilege and institutional racism; include structured and supported opportunities to work with Indigenous peoples and communities; and be underpinned by clear responsibilities and accountabilities for all those working in the sector (Prout et al., 2014; Beavis et al., 2015; Bullen and Flavell, 2017; Wettasinghe et al., 2020; Yashadhana et al., 2022). Elders' articulating that what is needed to age well is not just care, but love, is a critical contribution of this study. Elders made numerous practical suggestions about training up local Aboriginal workers and resourcing family members to enable the provision of not just culturally safe care but an effective model of culturally led support as Aboriginal people age. As noted earlier, such measures could not only provide the support that Elders desire and deserve, but also improve employment outcomes and intergenerational wellbeing.

Conclusion

This study makes significant conceptual, methodological, policy and practice contributions to knowledge around ageing well for Indigenous people in Australia and elsewhere, in particular for those living in remote areas. It builds on and extends existing scholarship on the importance of Elder-led research and a holistic conceptualisation of wellbeing that is intrinsic to Aboriginal peoples' connection to Country, culture and community. The richness of the qualitative data is the result of an innovative methodological approach that meant the research was led by Elders and undertaken collaboratively with trusted researchers. The themes speak to both the barriers and enablers to ageing well for Aboriginal people in Walgett and elsewhere. The findings provide guidance on reform that is critically needed in policy and service design, including the valuable model of a communitycontrolled Elders organisation that provides a place to gather and connect, to share knowledge and humour, and bring critical community leadership and advocacy. They highlight that any policy response must not just focus on reform in aged care, but also on the health, housing and social sectors, amongst others, centred on a holistic concept of wellbeing. Australia, like other colonised countries, is grappling with how to provide redress and reparations for the ongoing harms of dispossession

and institutional racism, alongside a growing need for better services and support for an ageing Indigenous population. This study highlights the value to research, policy and service delivery of listening to and learning from Elders, of centring Indigenous knowledges and worldviews, and of bringing a more holistic conceptualisation of wellbeing to the understanding of what it means to age well.

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Competing interests. The authors declare no competing interests.

Ethical standards. This study was undertaken with ethical approval from the NSW Aboriginal Health and Medical Research Council Ethics Committee (1574/19) and the UNSW Human Research Ethics Committee.

Notes

- 1 In the Australian context, Aboriginal, Indigenous and First Nations are often used interchangeably; in this article, Aboriginal is used as it is the term preferred by the Dharriwaa Elders Group (DEG). Many Elders identify themselves by their nation or language group, which in Walgett includes Gamilaraay, Yuwaalaraay and Ngayiimbaa. Indigenous is used in the context of international literature.
- 2 There are different conceptualisations of 'Elders' used in different contexts in Australia. This article draws on the DEG definition which refers to Aboriginal people aged over 60 as Elders.
- 3 'Country' for Aboriginal people is a multi-dimensional concept in which land, water, air and animals are interconnected with culture, knowledge, relationships and identity; 'Aboriginal people have little room to separate themselves from Country as they are embedded within it' (Kingsley *et al.*, 2013: 682). In this context, it is used by Elders to refer to Walgett and surrounding areas.
- 4 'Water pups' are juvenile rakali (Hydromys chrysogaster), an Australian native water rat now rarely seen in Walgett due to mismanagement of rivers.
- 5 Such as having Aboriginal-specific programmes, Aboriginal or culturally proficient staff, and culturally safe service venues in the community (Wettasinghe *et al.*, 2020: 11).

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