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Looking out across the front yard: aboriginal peoples' views of frailty in the community – A qualitative study

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ABSTRACT

Objective: Frailty is one of the most significant challenges to healthy ageing. Aboriginal Australians experience some of the highest levels of frailty worldwide, and despite this, no studies have explored frailty from an Aboriginal perspective. This is important because Aboriginal understandings and priorities in frailty may differ from Western/mainstream frailty frameworks. Furthermore, this lack of research severely hampers healthcare planning and service delivery. As a starting point, this study aims to understand the experiences, attitudes, and perceptions that Aboriginal older adults hold regarding frailty.

Design: A qualitative study that utilized the Indigenous research method of Yarning for data collection as a culturally appropriate process for engaging Aboriginal peoples. Yarning circles and one-on-one yarns with 22 Aboriginal adults aged 45+ years living in one Australian capital city took place online and over the phone to explore the views that Aboriginal adults hold around frailty. Data were analysed thematically by Aboriginal researchers.

Results: Seven key thematic areas were identified: (1) Keep in with culture; (2) Physical markers of frailty; (3) Frailty throughout the life course; (4) Social, cultural, and psychological understandings of frailty; (5) We want information about frailty; (6) Appropriate and positive wording; (7) Frailty assessment.

Conclusions: There was interest and engagement in the concept of frailty by Aboriginal older adults and approaches to frailty that extend beyond the physical to address cognitive, psychosocial, cultural and spiritual domains are likely to be more acceptable to this

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SUSTAINABLE DEVELOPMENT GOALS

Good health and well-being

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population. Culture and community connectivity are essential elements in preventing and alleviating frailty and have wider positive implications for Aboriginal health and wellbeing. Existing tools in practice to assess frailty are not aligned with Aboriginal cultural norms. Culturally appropriate frailty assessment methods co-designed with the community which incorporate holistic and multidimensional approaches are urgently needed.

Introduction

From a Westernized clinical perspective, frailty is characterized by reduced physiological reserve to adapt to minor health stressors, and thereby increases the risk of adverse outcomes including death (Clegg et al. 2013). Identifying and responding to frailty is important for supporting those most severely affected, providing opportunities to implement tailored interventions to prevent or delay progression, and facilitating shared decision-making (Boreskie et al. 2022). The WHO's Clinical Consortium on Healthy Ageing underscores the need for proactive identification and efficient assessment of frailty in a range of settings and population groups as one of the top 10 priority areas in its 2020 agenda (World Health Organization 2016). It is also recommended that all older adults be routinely screened for frailty using a validated tool in clinical practice (Dent et al. 2017).

Frailty is a global issue affecting between 12% and 24% of community-dwelling older adults and its prevalence increasing with age (O'Caoimh et al. 2020). However, the frailty literature relevant to Indigenous populations is limited, and a recent scoping review of nine studies mapping frailty in Indigenous adults within settler colonies found Indigenous populations experience disproportionately high levels of frailty with onset occurring in younger age-groups when compared to their non-Indigenous counterparts (Lewis et al. 2021). Some of the highest levels of frailty worldwide have been reported among Aboriginal adults aged 45+ years in remote regions of Australia with an overall prevalence of 65%, and very high levels of frailty in those aged 45–49 years at 55%, increasing to over 83% for the oldest age group (80+ years) (Hyde et al. 2016). Importantly, wider determinants of health such as low socioeconomic status are recognized drivers of frailty and inequality (Hale, Shah and Clegg 2019). Aboriginal and Torres Strait Islander peoples (hereafter respectfully referred to as Aboriginal), experience greater socio-economic disadvantage and health disparities compared to the general population; this is known to be underpinned by historical injustices, systemic discrimination, cultural marginalization, and colonization (Dudgeon, Milroy, and Walker 2014). Racism and inter-generational trauma also have a major impact on health and social disparities for Aboriginal peoples, and likely contribute to the high rates of frailty (Radford et al. 2017; Thurber et al. 2021).

There is no consensus on an operational definition of frailty among the experts. Many tools to identify frailty have been developed (Van Damme et al. 2021), largely based on one of the two most dominant frailty conceptualizations. The frailty phenotype which defines frailty as a physical syndrome, based on age-related biological changes and physical features (Fried et al. 2001) and the frailty index which is based on the proportion of health deficits (signs, symptoms, health conditions, disabilities, laboratory test abnormalities) a person has accumulated (Mitnitski, Mogilner, and Rockwood 2001). Clinical

definitions are important, however, capturing the voices of older people is also key to understand their perspectives and experiences of frailty and to drive improvements in healthcare (Lekan, Collins, and Hayajneh 2021). This is important because the way that people understand frailty has implications for how they engage in frailty-related health communication and services, and whether they believe it may be ameliorated. Previous work shows that older people tend to conceptualize frailty as a multidimensional phenomenon with physical, social, and psychological aspects (Durepos et al. 2022; Schoenborn et al. 2018; St. John et al. 2019) and that some older people may reject the label of frailty, even when clinically identified (Pan, Bloomfield, and Boyd 2019; Warmoth et al. 2016).

The concept of frailty does not easily translate across cultures. In order to address frailty in Aboriginal communities, we need to understand that Aboriginal concepts of health extend beyond an individualized Western clinical definition. Instead, health is understood more holistically, to include not just the health of the individual but the well-being of the family and wider community (Dudgeon, Milroy, and Walker 2014). These cultural differences in understandings and approaches need to be acknowledged and foregrounded in the support and care offered, particularly if identifying frailty and what it looks like for older Aboriginal people. Despite the large burden posed by frailty for Aboriginal adults, no research has explored the views of frailty from an Aboriginal perspective (Lewis et al. 2021). This is a significant knowledge gap as Aboriginal people tend to emphasize strengths-based approaches and broader holistic views of health and ageing (Yashadhana et al. 2022). This means that how Aboriginal people perceive, understand and prioritize frailty can differ from existing conceptual and operational definitions of frailty. Furthermore, while the need for culturally co-designed and clinically valid tools for Aboriginal communities has been recognized outside the frailty landscape (Westerman and Dear 2023), tools to identify frailty based on Westernized models remain the default. A culturally relevant understanding of frailty is essential for preventing and delaying adverse health outcomes and informing ways to support and maintain health for Aboriginal people in later life.

This study aimed to address significant gaps in research knowledge from an Aboriginal perspective to better inform approaches to frailty and facilitate future culturally appropriate frailty screening and care planning and service delivery. Specifically, we sought to understand the experiences, attitudes, and perceptions that older Aboriginal people in New South Wales (NSW) hold about frailty, its screening, consequences, and needs and suggestions for frailty-related management.

Materials and methods

Qualitative methodologies were used as the most effective way to gather rich descriptions of complex perceptual approaches and important insights from a purposive sample of urban-based participants related to the phenomenon under investigation (Sofaer 1999). We employed Indigenist research approaches which foreground Aboriginal peoples in the research process and honour Aboriginal ways of knowing, being and doing (Martin and Mirraoopa 2003). Yarning was utilized for data collection as a culturally appropriate process for engaging Aboriginal peoples (Bessarab and Ng'andu 2010). Yarning is conducive to Aboriginal ways of doing things. It is a conversational

process that involves storytelling and development of knowledge, privileging Aboriginal voices and allowing for safe collection of data (Bessarab and Ng'andu 2010). Unlike traditional focus groups and interviews, yarning is more focused on equal power relationships, establishing relationality and is reliant upon cultural protocols (Walker et al. 2014). In this context, social yarning and research topic yarning was employed. Social yarning typically precedes research topic yarning in the same session. It involves the researcher and participant(s) getting to know each other through informal and often unstructured conversations, and serves as a foundation for building trust and relationships (Bessarab and Ng'andu 2010). Research topic yarning is a conversation with a purpose, providing a culturally acceptable way to generate focused discussion regarding participants' views through semi-structured conversations (Anderson et al. 2021; Bessarab and Ng'andu 2010).

Participant recruitment

Older adults were purposively recruited through an Aboriginal Community Controlled Organisation located in Sydney NSW that is frequented by older Aboriginal people who promoted the study advertisement flyer. Engaging through a trusted organization ensured the study flyer was seen by older Aboriginal adults in Sydney and increased the likelihood that the role of yarning in this context was a familiar practice. NSW is home to approximately one-third of Australia's 812,728 Aboriginal and Torres Strait Islander peoples (Australian Bureau of Statistics 2021), with over 60% of those aged 45 + years residing there (Temple et al. 2020). Sydney, the capital city, consists of several local districts of heterogeneous socioeconomic profiles and is home to the largest Aboriginal population. According to the 2021 Census, approximately 90,939 people in Sydney identified as Aboriginal and/or Torres Strait Islander, with 96% identifying as Aboriginal (Australian Bureau of Statistics 2021). Following national trends, the Aboriginal population in Sydney have a younger age profile than the non-Aboriginal population with a median age of 24 years and 23.3% aged 45+ years (Australian Bureau of Statistics 2021). The median weekly family income for Aboriginal households in Sydney is \$1779, slightly above the national average for Aboriginal households at \$1507 (Australian Bureau of Statistics 2021). Study eligibility included: self-identifying as Aboriginal and/or Torres Strait Islander; currently residing in Sydney; and aged 45+ years. This age bracket is considerably younger than other definitions of 'older', reflecting the higher burden of frailty experienced by Aboriginal people at younger ages (Hyde et al. 2016).

The study flyer was distributed via the organization's social media (Facebook, Instagram), webpage, organizational email networks, posters, and through word-of-mouth. The study flyer included the research team contact details (email and phone numbers) and the Participant Information Sheet and Consent Form (PISCF) in electronic online format, which could be accessed via a weblink on the study flyer. For those who expressed interest in the study by contacting the research team directly either by phone or email and could not access or did not feel comfortable or confident navigating the PISCF online, a hardcopy PISCF was mailed with a postage-paid envelope for return of the consent form. The PISCF included the option to select the preferred study participation method i.e. yarning circle or one-on-one yarn. Participant reimbursement was included with an AUD\$100 Visa gift card at the end of data collection as a thank-you for the

participant's time taking part in the study. Since this research took place during the COVID-19 pandemic, information was provided on alternative methods that would be offered if in-person research was suspended due to pandemic restrictions. Following the consent process, the research team contacted the participant to check eligibility, get participant baseline characteristics, answer questions, and confirm informed consent had been noted. Preference to participate in either a yarning circle or one-on-one yarn was confirmed, and data collection was scheduled as convenient to the participant.

Data collection

At the time of the study, NSW went into a state-wide pandemic lockdown for several months. This necessitated moving face-to-face data collection to phone or online platforms. Participants were contacted by a member of the research team and offered alternative participation methods which included participating in an online yarning circle or a one-on-one yarn, either online or via phone. Fifteen opted for one-on-one yarns (twelve by phone, three online), and seven chose online yarning circles. Data collection took place between September and October 2021.

A standard Yarning discussion guide was developed based on existing published literature exploring older adults' perspectives on frailty and frailty screening (Schoenborn et al. 2018; Van Damme et al. 2020). The guide was refined and adapted by the study team to reflect the study aims and to ensure the appropriateness of the questions with guidance from an Aboriginal Elder (RC). The guide was administered by Aboriginal researchers ETL and LH for women's business and AH for men's business who were trained in qualitative methods (Appendix 1).

Online gendered yarning circles and one-on-one yarns with an Aboriginal research team member were conducted using Microsoft Teams, either via a web browser which does not require a subscription or Teams desktop application; initial consultation has found that Teams is user-friendly and feasible for online focus groups (Menary et al. 2021) and online yarning circles with Aboriginal Australians has been reported to be an acceptable and feasible alternative to face-to-face research methods (Anderson et al. 2021). For those participating online, an instruction training test call with a member of the research team prior to data collection was offered to accommodate those unfamiliar with Teams, who wanted to test their device, or who lacked technological confidence. Furthermore, a guide on how to use Teams was provided to all participants. Yarning circles and one-on-one yarns began with social yarning, and this was facilitated by initially encouraging those in the yarn (including facilitator) to introduce themselves, often sharing their relationship to Country or the community, along with any information they wished to discuss at that moment. Yarns then moved into research topic yarning, guided by the Yarning discussion guide, to obtain information related to the research aims. Facilitators discussed information about the project, and covered areas such as confidentiality, reassurance that there was no right or wrong discussion, that everyone's views and opinions are important, and that they did not have to participate in all the discussions if they did not feel comfortable or would prefer just to listen. For online yarning circles, it was encouraged to speak one at a time so everyone could hear what others were saying. During the yarns, the facilitator presented participants

with material that contained several examples of frailty tools that are used in health-related settings (Appendix 1). This material was shown to participants using the Teams screen-sharing function. For those participating over the telephone, the examples of the frailty tools were emailed to the participant at the start of the interview to view when prompted. For participants who had confirmed they would not have access to email during the interview, the material was posted in the days leading up to data collection to ensure sufficient time for the material to arrive, with participants instructed to only open the material when prompted by the facilitator during the data collection. While there was no time limit imposed on the duration of yarns, one-on-one yarns took an average of 44 min, while yarning circles averaged 73 min. Both came spontaneously to an end when participants felt comfortable their stories had been shared. These were audio-recorded, and field notes were completed and checked with participants during data collection.

Data analysis

The audio-recordings were transcribed verbatim using a professional transcription service, with transcribed data managed using NVivo software for subsequent analysis. We employed inductive thematic analysis, a systematic way of organizing, analyzing, and describing the content of the recorded/transcribed discussions incorporating researcher reflexivity (Braun and Clarke 2006). Initially repeatedly reading the transcripts, ETL independently coded all transcripts and LH independently coded 50%. Having a second researcher code a subset of the data was used to reveal any individual bias, or themes that may have been overlooked (O'Connor and Joffe 2020). This approach also allows for alternative interpretations and understandings of what had been said to become available for discussion between researchers. In our study, having a second researcher independently code half the transcripts typically exceed what is reported in other studies, ensuring trustworthiness of the data (O'Connor and Joffe 2020). After independent analysis of the transcripts, a list of themes containing relevant codes was jointly developed (ETL, LH). A third researcher (GK) independently reviewed the list of themes (established by ETL and LH) for accuracy and contributed to the refining of categories and themes. The researchers held iterative discussions and interpretations were reviewed and verified by researchers within the study team. Participants were invited to a community feedback event when lockdowns had lifted as an opportunity to share the findings with community members and feedback was sought to establish trustworthiness. Trustworthiness of the interpretations was enhanced by providing direct quotes from participants.

Results

A total of 22 Aboriginal older adults participated in the study (Table 1). Seven participated in yarning circles (women's yarning circle $n = 4$, men's yarning circle $n = 3$) and 15 participated in one-on-one yarns.

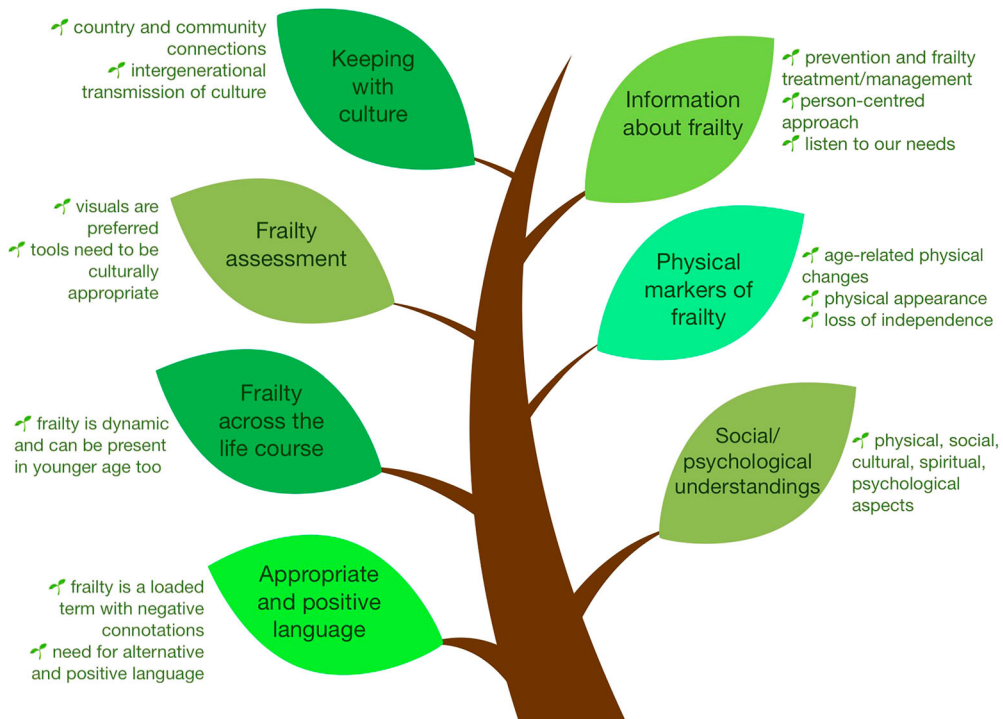
Seven key thematic areas were identified (see Figure 1) which are discussed in further detail below and providing examples of older Aboriginal voices.

Table 1. Participant characteristics ($n = 22$).

	<i>N</i> (%)
<i>Indigenous Status</i>	
Aboriginal	22 (100)
Torres Strait Islander	0 (0)
Aboriginal and Torres Strait Islander	0 (0)
<i>Gender</i>	
Male	6 (27)
Female	16 (73)
<i>Age group (years)</i>	
45–49	3 (14)
50–54	5 (23)
55–64	6 (27)
65+	8 (36)
<i>Health service contact in past year either for</i>	
Self	13 (59)
Family/friend	2 (9)
Both self and family/friend	7 (32)
<i>Current or past caregiver for an older person</i>	
Yes	11 (50)
No	11 (50)

The ‘front yard’ approach – keep in with culture

It was apparent that the term frailty was not commonly used among participants, if at all. In contrast to Westernized understandings of frailty, the effect of frailty on individuals was in fact secondary. Discussion of health and wellbeing could not be detached from being in community. A central tenet of all discussion was the importance of having strong cultural,

**Figure 1.** Key thematic areas identified from the yarning circles and one-on-one yarning.

community, and Country (traditional ancestral homelands) connections. This pre-empted and shaped all and any discussion of what frailty meant. These connections were consistently emphasized by participants as an essential element for fostering good health and wellbeing.

Aboriginal people, keep in with culture, keep in some sort of active group ... For us, it's always coming back to gather as a community and getting back to country if you can. (One-on-one yarn, Female, 45–49yrs)

Connection to the community was not merely the presence of human interaction, whether in-person or via technology, it was expressed as a fundamental sense of connection that can be understood as feeling included, contributing to, and having a sense of belonging in the community. Having the opportunity to go out and be physically present within the community where possible was acknowledged as being of great importance.

That's the thing, home care, we'll clean your house and we'll mow your lawns and that prevents me from going into a home [aged-care facility], but I still want to be somewhere, I want to do something. I still want to be a part of my community ... I think for all of us, it's having a sense of belonging. (One-on-one yarn, Female, 50–54yrs)

Another participant went on to explain that Aboriginal understandings of connection to community tend to differ from mainstream views. Members of the community, they suggested, want to know about and be involved in the lives of others. Community is everybody's business. The concept of a 'people stream' was raised as an important and enabling factor to support the health and wellbeing of older Aboriginal people. Here the participant reflects on a story shared by one of his Elders on the importance of community not only being there but being visible.

This Western idea is all upside down. People flock to their backyard, that's the main part, you get that private backyard ... We mob [Aboriginal people] stick together and we do it in the front yard. She [an Elder] talked about the people stream. The footpath is the people stream going past and you're connected. People come up and sit on the front veranda. The gubbas [non-Indigenous person] are all making it out the backyard. You went out to her backyard and there was an old car out there. That's where you park your car. Everything was on the front. I went 'Wow.' What can we do in communities? We've got to create community and create connection with other people. (Yarning circle, Male, 50–54yrs)

Intergenerational connections were further described as having far-reaching positive impacts on wider health and wellbeing in later life whereby older adults felt 'valued' and 'respected' and that relationships were reciprocated through Elders sharing traditional knowledge. These intergenerational connections were perceived as vital in ensuring the preservation of cultural continuity and learnings for future generations. This is illustrated by a participant reflecting on the experience of visiting one of the very few Aboriginal aged-care facilities. Here the participant describes the positive impact this facility, which was situated in an Aboriginal community, had not only on the health and wellbeing for the older adults but across all generations.

It was right smack in the middle of the community. It wasn't stuffed off in some corner. Those old people were connected to mob. They were teaching young people language. They were teaching them art. They were talking about culture and they were respected people. It was the happiest aged-care facility I've ever seen. I thought that was really awesome. (Yarning circle, Male, 50–54yrs)

Physical markers of frailty

When participants were encouraged to explore what frailty meant for individuals, there was general agreement that ‘frailty’ was difficult to define, and acknowledged it could mean different things to different people. However, for all participants, when asked to describe frailty, there was a focus on physicality, with an emphasis on physical appearance.

Frailty was often described in terms of ‘withdrawn in the face’, ‘weak’ and ‘thin’. There was strong consensus that people who were frail were often reliant on walking aids, had poor mobility, and were less active than they once had been. Frailty was most often discussed in the context of something that occurred in older age, and for some participants, frailty was viewed as an indicator of nearing end-of-life.

It means an elderly person who is not moving around, needs more than normal help to do things. Can’t walk. Can’t lift anything, they’re too frail. Their bones, their body has become too weak to do anything. (One-on-one yarn, Male, 65+yrs)

There was strong agreement that frailty impacted a person’s ability to perform daily tasks such as shopping, housework, or transportation. In this way, it represented a perceived loss of independence and required support from family and/or formal services to carry out these activities. Still, views on frailty differed including why the subsequent loss of independence occurred. A minority viewed frailty as independent of other conditions, and not precipitated by a pre-existing condition. In this sense, frailty was viewed as the primary cause of a person’s loss of independence and could exist in the absence of other diseases.

‘They’re pretty frail.’ They’re not sick, they’re not dying or those things, but they’re frail, and they need a lot of assistance, but not in the diseased sense. (One-on-one yarn, Female, 55–64yrs)

For others, the concept of frailty was strongly linked to illness. These participants often spoke of conditions such as arthritis, osteoporosis, and Parkinson’s disease whereby the presence of these conditions ultimately impacted a person’s mobility and ability to function in everyday life, and so this was perceived as frailty.

So, he said lifting the mug with one hand, it killed him. I think it’s from the arthritis. So, doing it two-handed, it makes it a bit easier but it’s still a struggle. He you would class as frail. (One-on-one yarn, Female, 65+yrs)

‘frail can be at any time’ – frailty throughout the life course

While frailty was largely discussed by participants in the context of advanced age, there was some discussion that frailty could occur throughout any point of the life course.

Frail doesn’t really mesh with aged, so you can’t just replace it with aged, because frail can be at any time, I guess, any age. (One-on-one yarn, Female, 55–64yrs)

Participants spoke of the onset of frailty in younger ages as often being precipitated by an illness, injury or disability which resulted in a person experiencing frailty.

And that’s the thing, I don’t think frailty really has an age limit. I mean, if you see a little kid that’s got cancer or something, they’re frail. (One-on-one yarn, Female, 50–54yrs)

Participants who spoke of frailty occurring at any life stage were more likely to view frailty as dynamic – a state which you could move in and out of from as opposed to a more permanent state which was most commonly perceived in the context of advanced age. This was often described in the context of the participant's own life experience of perceiving themselves as either 'physically' or 'mentally' frail at one point in time and who have since recovered.

I've gone back to just being myself. Only 'til now I start to feel – I was frail back then. I was actually quite bad. I was in a really bad place. (One-on-one yarn, Male, 50–54yrs).

Social, cultural, and psychological understandings of frailty

There was broad consensus that frailty encompassed more than just a physical component and entailed a holistic view including social, psychological, cognitive, spiritual, and/or cultural aspects. In this sense, frailty was understood to be multidimensional, and interrelated to a range of life influences.

If you're unwell, your spirit's unwell, your body's unwell. (One-on-one yarn, Female, 50–54yrs)

In one yarning circle, the discussion moved away from the impact of frailty on the individual to focus on the concept that frailty impacts the Aboriginal community as a whole, and indirectly referencing the impacts of colonization. In this context, frailty was conceptualized as something that could be experienced collectively by the community, with the fracturing of Aboriginal culture viewed as a causative factor.

With fragility I kind of think of our mob as having mass fragility. We've suffered so many years. I don't need to tell you mob. I look at our mob and I see cultural fragility. So much work to be done there to try and help people. (Yarning circle, Male, 50–54yrs)

There was strong consensus that other domains of frailty existed and could be distinct from physical markers. This was often associated with mental and cognitive impairment, including depression and dementia, where a person could be physically fit, yet mentally frail.

I reckon' he's probably getting towards starting to get dementia or something. His memory's failing. I would say he's mentally starting to become frail but physically, unbelievable. I go to the gym with him and he just kills me. (Yarning circle, Male, 45–49yrs)

Other aspects of frailty were largely conceptualized in how people perceived themselves, their thoughts, and attitudes. There was a strong perception that if a person was to think of themselves as 'old and frail', 'give[n] up hope' or if a person lacked 'self-confidence' or 'purpose' this could be suggestive of, or cause frailty.

So, my mother'-in-law's 76,'and she'll sit there' 'I can't do this,' and I go, 'Well, you know what? All I can hear is a lot of excuses there, Mum.' She goes, 'I know.' And, I go, 'Well, if you don't use it, you lose it. You were all right five years ago, so if you want to do something, do it.' It's all a mental state. (One-on-one yarn, Female, 45–49yrs)

Inversely, the importance of having a positive 'frame of mind' and a 'sense of purpose' was described as being protective from or alleviating frailty. This included identifying the things that people can still do even if illness or frailty restricted aspects of their

life, such as, being able to fulfil cultural obligations as an Aboriginal Elder, for example passing down knowledge to the younger generations.

You're passing on the knowledge, and it's getting rid of that, 'I'm just a useless old person.
(One-on-one yarn, Male, 65+yrs)

There was a strong sub-theme around the social aspects of frailty. Most participants perceived social isolation and loneliness to be highly prevalent amongst older Aboriginal people and were viewed as either causing or worsening frailty. For one yarning circle participant, the combination of frailty and loneliness significantly impacted wellbeing.

I think that loneliness with frailty would be a catastrophic part that you'll have to try and work through, you'll have to actually be able to acknowledge it, and sometimes we don't because I think it's hard for people to actually understand what's happening to them.
(Yarning circle, Female, 65+yrs)

Participants provided suggestions on how communities might combat this including with social gatherings and activities including Elders' groups, arts and crafts, and Aboriginal support groups. It was highlighted that to effectively engage older Aboriginal people, services need to be based locally, accessible and be affordable. Several participants preferred that these services be delivered by Aboriginal organizations, which were perceived to be more culturally appropriate.

I would also like them to be able to try and find culturally appropriate services instead of sending me to a doctor, they'd refer me to the AMS [Aboriginal Medical Service] rather than just a general GP, if there's an AMS available. (One-on-one yarn, Male, 55–64yrs)

We want information about frailty, but 'they've got to listen'

Participants were open to receiving information about frailty, cautioning that how health professionals conveyed this information was paramount. Discussion often shifted to Aboriginal people being proud, with a mistrust of mainstream health care due to discrimination and stereotyping, and as cultural fracturing had occurred, it was crucial that culturally competent, compassionate, honest, respectful communication is used. A key aspect is to focus on positive attributes, such as what the person can do and not just on their deficits when discussing frailty and ageing. An underpinning priority across all discussions was to employ a person-centred approach in listening to what the person needed and respecting their wishes in decision-making.

They've [health professional] got to listen to the individual, which they don't, and they think that they know best. They don't. It's the client, or the tenant, or the patient, that knows best what their body's telling them. The other people aren't in their body and they don't know what their specific needs are. (One-on-one yarn, Female, 65+yrs)

Participants felt they needed to be empowered. The information they most wanted was to know the trajectory of frailty and what could be done to prevent, treat, and/or manage their condition.

I'd like to know if they could let me know at what rate it was going to progress, if there was anything that I could do to slow down that progress, what degree of frailty that I'm going to

have, and would I still be able to live at home. Things like that. (One-on-one yarn, Female, 65+yrs)

Other information needs arose pertaining to frailty information focused on this sense of self-management and wanting to know about appropriate nutrition and exercise, availability of Aboriginal-specific frailty programmes and support groups, and alternate treatment and management. Approaching health holistically, included the importance of supporting those who were close to the person living with frailty.

To get me in contact with other Aboriginal support people in the community for that emotional support as well. So, it's not just about the biological disease of the body, it's about all these other factors around it, so looking at it from that perspective. There's a socio-logical, imaginative perspective, this is Jo, Jo is sick, but not just look at Jo as a biological sickness, but how many people around Jo that are also affected by their illness and how can we support all those other alternatives. Instead of just putting me on medication, maybe look at going swimming and that sort of stuff. (One-on-one yarn, Female, 50–54yrs)

Appropriate and positive wording

Although most participants had heard the term, many stated that frailty was not a word used in everyday conversations among community members. Instead, it was confined to the medical landscape. While some participants felt that it was acceptable for health professionals to use the word frailty as it was understood as a medical issue, the majority felt alternative words would be better. For these participants, the term frailty was a loaded term, viewed as a 'white man's word', suggesting negative connotations such as 'incompetent' and 'weak' – reducing a person to just their condition.

I don't like the word frail. I think it's horrible, because for me it diminishes you as a person. It's not recognising you as a person, it's only recognising what's happening to you. (One-on-one yarn, Female, 50–54yrs)

Several participants highlighted that Aboriginal people have been labelled all their life and commenting on the impact on individuals and community. For these participants, labelling a person frail could be detrimental, causing some to give up on their health and negatively impact wellbeing.

Because I think too, you might not feel great in yourself and you know things are changing, but when someone labels you frail, it's almost like it changes your own mindset to go, 'Okay. I might as well give up.' (One-on-one yarn, Female, 50–54yrs)

Most spoke about the need for alternate wording as language used on existing frailty tools could have negative connotations for Aboriginal people. Words might not easily be transferable, translatable, or understood by someone outside of the medical field.

They're words that you don't normally use. Like 'delirium', that word never comes up in our conversations. Falls do. Institutionalised doesn't. Somebody I think institutionalises somebody who really likes to be in jail because they feel safe in there. (One-on-one yarn, Female, 65+yrs)

Participants who offered suggestions for alternative wording to frailty suggested 'not so strong', 'evolving' and 'maturing'. There was a strong consensus that health professionals use more strength-based positive wording when discussing frailty with older Aboriginal people.

Part of aging in Aboriginal culture, as you know, is we move on to become a little bit more of a role model and maybe if we could use a positive word that we already use to describe our aging. (One-on-one yarn, Female, 50–54yrs)

There was acknowledgement that different communities may preference different Aboriginal words and therefore this could be considered when designing services and holding discussions around frailty as wording would be dependent on the local dialect.

The local dialect of the people. Aboriginal words. My two words are nyorn and winyarn. ‘Poor fellow.’ More or less, that’s what it means, how you say it too. ‘Nyorn winyarn. He winyarn. She winyarn.’ We know something’s wrong. That sounds better than frail. I don’t know why. (One-on-one yarn, Female, 55–64yrs)

Frailty assessment

Most participants perceived existing frailty tools as inappropriate for older Aboriginal people. Participants agreed that a tool to assess frailty must be easily understood, consider the person’s cognition and education levels, be applied sensitively, and be culturally appropriate. Most favoured tools that are short in length and incorporate visuals. Visuals were said to be helpful when wording may not be easily understood and could be used as an alternative to complex medical jargon.

I actually like the visual description, because if I look at the first three, so to me that’s someone going about their life, but when you start to look at the people with the walking sticks, the walking frame, and then someone helping them, and then the wheelchair, and the bed. To me, they’re great visuals because that tells a story for me. (One-on-one yarn, Female, 50–54yrs)

For some participants, visuals and descriptions used in existing tools did not resonate, and cultural appropriateness was questioned. In this context, it was perceived to not be relatable and reflect the Aboriginal community’s experience and cultural norms.

The pictures to me look advanced, Western worldview approach. It looks like that’s a whole bunch of people who are quite well-off. Think of people’s access to wheelchairs. Wheelchairs are bloody expensive, not something that everyone can get their hands on. Even the walking sticks and the frame, if I look at those pictures I think of white, Western type people not frail Aboriginal people. (Yarning circle, Male, 50–54yrs)

Several participants spoke of risk factors for frailty such as social isolation, mental health and wellbeing as missing from existing tools and the wider family unit and support a person has available to them was also an important factor to consider in a frailty tool for Aboriginal people. This highlighted an area of discussion prevalent throughout the discussions in relation to engaging and addressing frailty of the individual by considering social, domestic, and community arrangements.

Nothing in those scales says anything about isolation. You’ve got to have the family history, don’t you? Who’s living at home? Who’s the support people? (One-on-one yarn, Female, 65+yrs)

Discussion

Overall, it is evident participants recognize frailty and were aware of its impact on individuals’ and communities’ health and wellbeing. It is also clear however that

understandings of, and concerns around frailty differ and tools used in practice are not aligned with Aboriginal cultural norms.

Importance of culture and community connections

The most salient finding in our study was the emphasis placed on cultural and community connectivity as an essential element to prevent and alleviate frailty and its wider role in facilitating positive perceptions of health and wellbeing. The importance of this connectedness has been identified in a Māori population where connection to traditional cultural practices and cultural identity were viewed as having a positive impact on the experience of frailty (Gee et al. 2021). Aboriginal Elders play a pivotal role in community through sharing traditional knowledge with younger generations, supporting family and communities, and strengthening the collective wellbeing of the community (Yashadhana et al. 2022). Keeping connected with the Aboriginal community and maintaining cultural roles was felt to moderate the effect of frailty and contribute to a sense of belonging, purpose, and cultural identity which would positively impact wellbeing for older Aboriginal people in our study. Indeed quantitative research in First Nations older people in Canada found cultural connection and identity was strongly associated with experiences of wellness despite the presence of frailty (Slater et al. 2022). This suggests that culture plays a central role in supporting older adults with frailty to achieve and maintain positive wellbeing.

Concepts of frailty

There was heterogeneity in the conceptualization of frailty. Frailty was largely understood by participants to occur with advanced age and to be associated with health conditions. Recognition that frailty could be present in the absence of disease by a very small number of participants aligns with the scientific community that tends to view frailty as ‘primary’ (age-related, absence of disease) or ‘secondary’ frailty (consequence of disease) (Won 2020). Still, the lay public often understand frailty to be an inevitable and irreversible consequence of the ageing process (Escourrou et al. 2018; Shafiq et al. 2023). Similarly the clinical understandings of frailty as a dynamic process where people can transition between different frailty states (Kojima et al. 2019) was echoed by participants who had perceived themselves as frail (mentally or physically) at one point during their lifetime and had since recovered. Physical limitations and appearance, mobility issues, and loss of independence were the most discussed visible descriptors of frailty, in keeping with other studies (Puts et al. 2009; St. John et al. 2019; Warmoth et al. 2016). However, physical domains were perceived as just one aspect of frailty. For our participants, frailty could span multiple domains interrelated with a range of life experiences, with several protective or causative/contributing factors to frailty across these domains. These findings are supported by other studies of older adults’ understandings of frailty to be a multidimensional phenomenon (Durepos et al. 2022; Puts et al. 2009; Van Damme et al. 2020). However, not commonly reported in the Western literature is the interplay of cultural and spiritual factors in frailty as identified in our study; suggesting these factors may be more prominent in certain population groups (Gee et al. 2021; Lekan, Collins, and Hayajneh 2021). For example, a study of African American

older people identified spirituality and religious practices to be important in the prevention and alleviation of frailty (Lekan, Hoover, and Abrams 2018). The continuing impact of colonization has resulted in many Aboriginal people experiencing intergenerational trauma and cultural dislocation (Dudgeon, Milroy, and Walker 2014). The notion of 'cultural fragility' experienced collectively by the Aboriginal community was an important finding. While Western models of health and illness tend to focus on individualistic problems and are disease-centric (Germov 2019), our findings better reflected a holistic Aboriginal worldview of health, which encompasses both the individual's and the community's physical, cultural, spiritual, and emotional wellbeing (Dudgeon, Milroy, and Walker 2014).

Communication and assessment of frailty

In the current study, frailty was not a word used in the community and labelling a person as frail was understood to have negative connotations for Aboriginal people and to be detrimental to wellbeing. This echoes research of Aboriginal conceptualizations of disability which found that for Aboriginal people, labels based on physiological characteristics, abilities, or impairments were viewed as culturally disrespectful (Ravindran, Brentnall, and Gilroy 2017). Discussing frailty with health professionals and information needs about frailty progression, prevention, and treatment were also key findings, and are supported by previous frailty research in the US (Schoenborn et al. 2018). The importance of culturally competent health professionals and taking a person-centred approach was highlighted. Culturally appropriate and respectful language is a core component of cultural safety in healthcare and is identified as an essential element to effectively engaging with older Aboriginal people (Chakanyuka et al. 2022; Wettasinghe et al. 2020). This is particularly important within an Indigenous context, where well-known barriers to accessing mainstream health services include racism and discrimination, stigma, inappropriate and culturally insensitive communication, transport barriers and costs (Wettasinghe et al. 2020; Wylie and McConkey 2019). Aboriginal Community Controlled Health Services deliver holistic, culturally safe, and comprehensive primary health care and address the wider determinants of Indigenous health (Pearson et al. 2020). This likely explains the strong preference by our participants that frailty-related health care and services to combat frailty be delivered by Aboriginal health services. Similarly to other studies (Durepos et al. 2022), a need for health professionals and services to provide a balance in relation to frailty was emphasized; in other words, not solely focusing on what a person cannot do and their losses or limitations, but a focus on strengths and positive attributes and a mindset that frailty was a challenge that could be overcome. Our findings suggest that tools to assess frailty in their current form do not reflect the complexity of our study participants' perceptions and experiences of frailty. Holistic approaches to frailty that include emotional and psychological wellbeing, social connectivity, community networks, and the support needs of the wider family were important elements that participants felt should be factored into the assessment of frailty. Tools that incorporate visuals were largely preferred as an alternative to complex medical terminology or where health literacy was lower, a finding which is supported in other Aboriginal study populations outside of frailty (Povey et al. 2016).

Limitations

This study is the first of its kind to explore the views Aboriginal Australians hold regarding frailty, and it is not without its limitations which should be considered when interpreting the results. The study was conducted in Sydney and as Aboriginal peoples are a diverse group (Dudgeon, Milroy, and Walker 2014), the generalizability of the results to other Aboriginal communities is unclear. However, given the legacy of colonization, these findings are likely to have relevance to other Aboriginal communities and possibly other Indigenous populations who share similar histories. The measurement instruments shared with participants have been designed for use by healthcare providers rather than by members of the public. Hence the results of this segment of consultation may only be relevant to the Aboriginal health workforce. Due to pandemic restrictions data collection was moved online and over the phone depending on the participant's preference, which may have affected the ability of the researcher to read non-verbal cues and how much was shared in the yarns depending on the participant's preference for in-person connection. It is also acknowledged that people were experiencing heightened social isolation and may have been more sensitive to health-related labels, hence impacting results. As most participants were women, gaining more insights from and culturally creative approaches to achieve further engagement from men are required in future research. Despite these limitations, our study provides the first insights into the views that older Aboriginal people hold about frailty and using research methodologies that allow the importance of this to emerge was key.

Implications

Frailty was associated with physical, psychological, cognitive, spiritual, social, and cultural factors; understandings more closely aligned with calls from others that approach frailty as multidimensional including physical, social, and psychological domains (Markle-Reid and Browne 2003). However, our findings suggest that multidimensional approaches to frailty within an Aboriginal context should be extended to include the wider determinants of Aboriginal health. In particular, the cultural determinants of health (e.g. connection to community/family, Country, cultural identity) which centre a holistic Aboriginal worldview of health (Verbunt et al. 2021) to be considered going forward in both the assessment and subsequent strategies to combat frailty to better reflect Aboriginal worldviews of health and frailty. Culturally and clinically valid frailty assessment methods co-designed with the community which incorporate holistic, multidimensional approaches to capture the factors perceived to be important in frailty to Aboriginal people are urgently needed in practice and policy. Furthermore, while there is a substantial body of evidence that mainstream interventions such as strength training and protein supplementation can prevent, delay progression and reverse frailty (Won 2020), multidisciplinary and multisectoral tailored approaches to frailty's prevention and management which extend beyond the clinical and address the social and cultural determinants of health are likely to be required. Lastly, our participants preferred a strength-based approach to frailty. Whilst strength-based approaches to healthcare and policy are advocated for by Aboriginal

communities, deficit discourse remains the default, portraying people in terms of deficiencies and is a barrier to improving Aboriginal health outcomes (Fogarty et al. 2018). A paradigm shift is required in frailty's assessment and management that moves away from a deficit-based model to a 'frailty-balance' (De Donder et al. 2019) whereby health professionals and services recognize Aboriginal people and their community's strengths, adaptations, and assets.

Conclusion

To better reflect Aboriginal understandings of, priorities in, and concerns around frailty; culturally appropriate approaches to frailty that extend beyond the physical to address cognitive, psychosocial, cultural, and spiritual domains are likely to be more acceptable. Culture and community connectivity are essential elements in preventing and alleviating frailty and have far-reaching positive impacts on Aboriginal health and wellbeing. Findings from this research indicate that existing tools to assess frailty are not aligned with Aboriginal cultural norms. It is crucial that this holistic notion of frailty be translated into culturally appropriate tools and strategies in this population to inform culturally meaningful frailty-related health care and services that are co-designed with the community.

Feedback to the community

A covid-safe in-person feedback lunch event at the Aboriginal Community Controlled Organisation in Western Sydney was held in 2022 when Covid lockdowns had lifted in NSW. Study participants and personnel involved in the research were invited as a thank you and to provide an opportunity to disseminate the findings to the study participants.

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Ethical statement

The study was approved by the Aboriginal Health and Medical Research Council Ethics Committee (AH&MRC; 1838/21) and the University of New South Wales Human Research Ethics Committee (UNSW; HC210542).

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

The participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data are not available.

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