Research
The (mis)matching of resources and assessed need in remote Aboriginal community aged care

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Aim: *To examine processes of aged-care needs assessment for Aboriginal people in remote central Australia to assist development of appropriate models of aged care.*
Method: *A qualitative study involving 11 semistructured interviews with aged-care assessors and two focus groups with Aboriginal community members.*
Results: *This paper reports four major themes concerning how needs assessments relate to realities of service delivery: cultural perspectives on aged care, context of service delivery, equity and access to services, and program (mis)alignments.*
Conclusion: *Disparities exist between assessment recommendations and service availability, with a potential mismatch between Aboriginal understandings of needs, interpretations by individual assessment staff and program guidelines. Incorporating a conceptual framework, such as the International Classification of Functioning, Disability and Health, into service guidelines to ensure structured consideration of a person's holistic needs may assist, as will building the capacity of communities to provide the level and type of services required.*

Key words: *Aboriginal, assessment, community care, Indigenous, remote aged care.*

Introduction

Aboriginal service users have a right to receive aged care that is aligned with their value systems and integrated with community life [1]. The provision of community aged-care services in remote contexts involves challenges that are framed by distance, isolation (both geographic and professional), a high workforce turnover and poor community infrastructure [2]. Exploration of the most appropriate models of community care for Aboriginal service users has been identified as a national priority [3], and recently, as part of the 'Closing the

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Gap' strategy, the adoption of coordinated and innovative models of care is being promoted to enable the maintenance of social and cultural connections and ageing 'on country' [1].

There is recognition internationally that distances as well as cultural incompatibility between providers and recipients are obstacles to the provision of quality health and human services in remote areas [4]. As in any service location, older Aboriginal people are required to undergo assessment to determine their level of need, which subsequently determines their access to support services and funding packages. Ideally, this leads to the provision of quality care within a functioning service system. Assessments involve conversations, and other interactions, between potential service users and the professionals who 'interpret the rules and regulations of society' [5; p.370]. These interactions involve (mostly) negotiations of interpretations of need, and are essentially based on culturally shared knowledge leading to categorisation and identity construction (the process that occurs when the person becomes, for example, a 'home care receiver') [5].

Findings from a small number of planning studies conducted in the central Australian region in the 1980s and 1990s [6–9] showed that Aboriginal people in the region have a preference for aged-care services to be community driven, that care must be delivered flexibly and that older people have a strong desire to grow old and die 'on country'. We also know that older Indigenous Australians have different health needs from both younger Indigenous Australians and older non-Indigenous Australians, indicated by poorer health status and higher needs for support services [10]. A small number of remote communities receive funding from the National Aboriginal and Torres Strait Islander Flexible Aged Care Program to provide a range of services according to local requirements [1,10], but most service provision to date has been funded by mainstream programs such as Home and Community Care (HACC) and Community Aged Care Packages (CACP).

While a previous study has highlighted inconsistencies in assessment practice in the central Australian region [11], little is known about the relationship of assessment decisions to the type and quality of care currently available and provided in remote Indigenous contexts. In our study we sought to examine processes of aged-care needs assessment for Aboriginal people in remote central Australia. More specifically, our objectives included gaining a better understanding of how clients and their families/carers participate in the assess-

ment process and what is most important to them; how different cultural perspectives are incorporated into the assessment process; and how identified needs are translated into a care plan in remote-community contexts. In particular, aiming to assist with the development of more appropriate models of aged care, this paper reports findings that explore how well needs assessments reflect the realities of service delivery in this context.

Methods

This was a qualitative study involving 11 semi-structured, in-depth face-to-face interviews with aged-care assessors and two focus groups with Aboriginal community members, conducted from late 2011 to 2012. Ethics approval was granted through the Central Australian Human Research Ethics Committee and the Flinders University Social and Behavioural Research Ethics Committee. Three researchers were involved in data collection and analysis, including an Indigenous researcher. Participants were asked questions relating to our study objectives, and interviews were typically conversational in style. All but one interview and one focus group were audio-recorded and transcribed verbatim; others were hand-transcribed as requested.

Study participants

To gain a broad insight into perspectives of aged-care assessment, participants involved in service provision as assessors, as well as direct service users and other community members, were engaged. Aged-care assessors (identified through purposive sampling) were invited by letter to participate in an interview, and recruitment was based on receipt of an informed consent form. Assessors were based in remote communities or in Alice Springs; their clientele was mostly Aboriginal, and they were interviewed as individuals and not as representatives of their employing organisations. Interview questions centred on the current work status and background of the individual, training, methods of assessment, decision-making and cross-cultural interpretations, and considerations of assessment and service provision. Participants had worked in directly related roles for periods ranging from 6 months to more than 20 years, and all but one were non-Aboriginal.

Two focus groups comprising Aboriginal service users and community members (four participants in one and three in the other) were organised by local aged-care coordinators in two communities (both within 300 km of Alice Springs). Focus group participation was determined by expression of interest on the day and completion of consent forms and interpreters were used as necessary. Questions for focus group participants involved their experiences of assessment and decision-making, as well as the needs of older people in their community and how these relate to service provision.

Data analysis

Analysis involved all three researchers, with themes reached by consensus. This involved a data immersion process using an open-coding system, with each transcript being read by at least two researchers, and a systematic process of cross-checking themes and supporting quotes. Data were then collated using NVivo software version 9.2 [12] and the themes finally agreed by the researchers. Quotes supporting the reported themes (see Table 1) are attributed either to individual participants using pseudonyms or to FG1 or FG2 for the focus groups.

Results

Four key themes addressing the relationships between needs assessment and service delivery emerged from the interviews and focus group discussions. Table 1 presents these major themes and subthemes and examples of quotes, with some quotes relating to more than one subtheme (we have coded the quotes for reference in the text). The first major theme – *cultural perspectives on aged care* – included issues such as the importance of relationships, family participation in care, and ageing at home and staying 'on country', as well as matters concerning wellness and cultural identity. Staff expressed their admiration at the amount of care provided to older people in remote communities and in town camps (in Alice Springs) while acknowledging carer burden and stress, as illustrated by quotes 1(f) and 1(g). The need and significance for older Aboriginal people to remain on their homelands often had greater influence on assessment outcomes than physical or medical requirements, resulting in hardships for both carers and the older person (quotes 1(c) and 1(d)).

The second major theme – *context of service delivery* – includes issues relating to staffing, housing, living conditions, and hardship and carer burden. Work roles are often fused with the unpaid family responsibility for caring during non-work hours. Quotes 2(e) and 2(f) demonstrate the difficult living conditions experienced by many older Aboriginal people, with homelessness and financial hardship frequently encountered. Cultural aspects to caring for an older person such as avoidance relationships and strict gender roles present particular challenges for assessors when developing care plans (see quotes 1(i), 2(a), 2(b) and 2(c)).

The major theme of *equity and access to services* involves barriers to service entry, poor communication and accommodation of cultural expectations (e.g. mobility, food preferences). Quote 3(e) exemplifies the assessors' awareness of a lack of appropriate services to provide for older people with higher care needs. Assessments may indicate a certain level of need that cannot be met, leaving people underserviced or requiring services to source funds elsewhere. Problems with quality service provision and uneven service access were also evident and included inequities between Aboriginal and non-Aboriginal people, as well as between town-based and remote Aboriginal clients. However, the situation was often far too complicated to be rectified by an increase in funding alone. Often, inadequate resources relate to poor community infrastructure, a lack of available people to work in commu-

Table 1: Major themes and subthemes

Theme and subthemes	Examples of supporting quotes
1. Cultural perspectives on aged care • Relationships • Family participation in care • Ageing at home/staying 'on country' • Wellness/cultural identity	(a) 'Out here it's different, they got families everywhere' (Lorraine). (b) ' "Who's your carer?" and start that, that can be an interesting conversation because there are very, very different perceptions of the role for us and for Anangu' (Grace). (c) 'Some people, it's really quite obvious they need to be in nursing home care but quite often we'll tick the one that's supported community accommodation but when you come to the blurb at the bottom you say you know that's what would be ideal but it doesn't exist out bush, you have to keep these people on country, but with the care and support that they need that families can't necessarily provide' (Paula). (d) 'Her care is really suboptimal, but we supported her to stay out there because . . . that was her choice . . . regardless of how physically difficult that was for her' (Grace). (e) 'Old people want young people to look after 'em' (FG1). (f) 'There's a lot that goes on outside of working hours. I actually think a lot of people in the town camps, particularly those who might need 24-hour care . . . or lots of supervision or whatever because their memory is going or they can't walk around, they actually probably get more care than you would get for someone who was living in a flat in Melbourne' (Yvette). (g) 'Most of the staff already coming from the same homes that these, you know, they're looking, they're carers away from work, you know they're looking after the same people that they're providing services to when they come to work' (Jane). (h) 'To be active members of the community which is – for a lot of oldies is the number one thing is to be an active [and] useful member of the community . . . So piling all the old ladies into the car and making sure they get to 'sorry' or whatever it might be you know, women's business, women's lore . . . When you see them when they first go and when you see them when they come back, they're totally different people.. I mean they're sick and decrepit and the whole bit but you see their colour's different, they're happier, they stand up straighter you know' (Kathy). (i) 'And then there's cultural stuff you know with avoidance relationships and things too so that they can't provide services, the helpers, the staff can't necessarily provide services for these people or they can't go to that part of the community so there's all sorts of other issues that just aren't considered when they put all this stuff together' (Paula). (j) 'An older Aboriginal person whose social worth and whole social world is completely bound up in their relationships to other people [in their community] . . .' (Grace).
2. Context of service delivery • Staffing • Housing • Living conditions • Hardship/carer burden	(a) 'And it's really hard if you don't have any male staff to provide personal care to the men' (Jane). (b) 'And it's like the provision of aged-care services has its ups and downs depending on staffing and can they actually get staff to run the aged care and how . . . [K]eeping staff is one of the biggest problems out there. And people not turning up for work for however many days' (Paula). (c) 'And there have been people who have been totally neglected even though an agency has been receiving money for CACP. So then what they say is we are just unable to work with them because we don't have Indigenous staff and rah, rah, rah, which is true' (Yvette). (d) 'No housing for him, well there's a housing crisis in that community' (Grace). (e) 'We're talking about some of the people living in some of the most poverty-like conditions' (Yvette). (f) 'I've got two old ladies at the moment . . . one is on an EACH package . . . and they have nowhere to live. They are living in the backyard of a house in one of the camps with a fireplace and some mattresses that we gave them. This lady cannot walk, she's incontinent and she lives on the ground in the weather. There's no tent, there's no nothing . . . She's choosing that arrangement and most of these people that are living in the community are choosing to be where they are even without support' (Benita). (g) 'And of course, I mean limited, really limited services out bush and even someone's on a community aged-care package they really only get a HACC level of service because a remote aged care, it depends on how many staff they've got and what facilities they've got to be able to provide an extra service. So mostly it's meals and laundry, maybe firewood collection, bit of transport, and doesn't matter whether you're HACC or CACP, you'll get the same' (Paula).
3. Equity and access to services • Barriers to service entry • Poor communication • Accommodating cultural expectations (e.g. mobility, food preferences)	(a) 'You know what do you do about these people who keep moving around and they'll go from one community for six months and then they'll come back and you've taken them off their [care package] but they expect to be able to go straight back on it again' (Paula). (b) 'Doctor's main one [to decide when someone needs a service] . . . all the piece[s] of paper to the office and they sort them out' (FG 2). (c) [Instruction on making damper in hot sand]. 'That's Aborigine way. White people can know that one' (FG1). (d) 'And the other thing about it is, when you go there, a lot of elderly people don't have as much support as opposed to a lot of the other people that live in town. You know they have CACP packages and there's only [one service] there that will go to town camps, the other people won't go, they won't go there on their own' (Crystal). (e) 'There needs to be more training and support put in place for these services . . . Often what happens too is people end up in hospital and sitting in the continuing care ward . . . and if they put that money into supporting what's going on in the community then those oldies wouldn't end up in hospital' (Kathy). (f) 'So instead of a restorative, supportive environment, they . . . are in an alien environment where people do not want to see them there [in poor living conditions] . . . and there's another thing about attitude, about what is OK and what's not OK. And us white folk coming in and saying "this is not OK" ' (Clare).
4. Program (mis)alignments	(a) 'There's a lot of our clients who are funded for instance by HACC, and so HACC is supposed to be a little bit of service but when in fact they are all qualified for EACH packages for HACC fees but there is none available. So we're providing them a seven-day service twice a day sometimes anyway on HACC funding' (Yvette). (b) '[Policy makers] want to be seen to be equitable between urban, rural and remote. So they're providing the same services regardless of where you live and it's not necessarily appropriate for your situation . . . A lot of our people out bush are . . . probably nursing home level of care and with a CACP you're only supposed to be low-level care and in theory they're not actually eligible for CACP. But so they're actually providing nursing home level care or looking after nursing home level care people out bush. We don't knock them back. We are allowed to approve them for EACH packages even though they're not available. I just find that really confusing' (Paula). (c) 'The whole system is set up for failure for Aboriginal people' (Clare). (d) 'And so there are some people on Community Care Packages, with much higher needs, but there aren't enough EACH packages to give them. So, um, we tend to – in the communities we tend to juggle them, so if someone's getting two hours, but they need eight hours, well then as long as we come in equal in time, that's what we do' (Benita). (e) 'When they do their child nutrition picnics . . . If I can take some older people along, it means firstly I don't have to organise it . . . and it can be quite time effective, but also the older person gets to country and there's that intergeneration transfer of cultural knowledge . . . It also means I can develop different kinds of relationships to people too, which is outside of these formal processes [of assessment], but . . . getting that broader picture of someone is really important. . . . Doesn't necessarily fit in a neat care plan, but it's important' (Grace).

nity care, or problems with staff attitudes and skills. Service delivery is problematic when circumstances of the users differ substantially from those in mainstream settings. For example, transience is often a feature of Indigenous community life, where older people may leave their community permanently or temporarily with changing carer roles (quote 3(a)). Some data revealed communication problems between service providers, and poor communication and understanding of the formal care system by Aboriginal community members was also evident (for example, quotes 3(b) and 3(f)).

The final theme reported here – *program (mis)alignments* – essentially relates to what is ideal and articulated in program documents compared with what is actually possible. As illustrated by quotes 4(a), 4(b) and 4(d) for example, assessors reported that many service users receive only a basic service, such as meals, laundry and firewood collection (as in quote 2(g)), despite being assessed as having high levels of care needs. There was also evidence that some assessors creatively develop care plans to satisfy program requirements while meeting what they perceive to be the real needs of individuals (quotes 4(d) and 4(e)).

Discussion

All participants expressed a strong belief that older Aboriginal people had a right to remain 'on country' for the duration of their lives, although some were challenged by the difficulties this presented. Preferences concurred with previous studies in palliative care where dying on one's homeland was highlighted as a cultural requirement, with non-fulfilment resulting in a negative effect on the natural environment [13,14]. However, as the current evidence suggests, the care requirements of older Aboriginal people in central Australia often remain unfulfilled if they continue to live at home. While it is not reasonable or feasible to expect resources to match those in more highly populated areas, the imbalance expressed by those in remote areas may result in a forced choice between physical hardship or being socially and culturally disconnected and eventually dying 'off country'. The strong family role in providing care for older people was similarly identified in earlier studies [8]; however, even the most supportive families need support themselves to maintain chronically ill and frail older people [13]. Similarly, community members in the Kimberley region expressed the value held in providing care for older relatives, yet found it difficult when also dealing with the responsibility of care for children and other family members [15]. In this context, gaps in support programs can result in extremely high carer burden, leading in some cases to families being unable to continue to provide the care required.

Earlier studies on the needs of Aboriginal older people have highlighted the requirement for community control and direction throughout the creation and implementation of human services, as without these, community members

become passive recipients in an intrusive system catering to mainstream standards [6,9]. Further, this allows for a safer process where the real needs of Aboriginal people are addressed, which may otherwise be misinterpreted, overlooked or not given priority according to common criteria [16,17]. Needs assessment is a form of identity construction created through locally ordered discourses where potential clients' self-presentations are negotiated and adapted to what is available in terms of home care [5]. However, even as a concept itself, 'need' may be understood differently for an Aboriginal person with a first language other than English [16] and without a shared cultural understanding of what it means to need care from a service provider [5]. Just as self-identified health status has been reported to be different in similar groups where language and remoteness generates distance from health labels and corresponding conceptual understandings [18], so too may constructs of aged care. Our evidence suggests that some assessors focus on the aspects of life contributing to an older person's wellness as a basis for developing a sense of need. For example, some took a broad view of care needs to include enabling ad hoc attendance at cultural obligations such as 'sorry camps' or 'lore meetings' despite these falling outside the traditional requirements of regular and ongoing care delivery, especially where living conditions appear suboptimal.

A more structured way of coming to these shared understandings may be possible by introducing a conceptual framework such as the International Classification of Functioning, Disability and Health (ICF) [19] to be used alongside formal assessment tools [20]. In this way, assessors are encouraged to investigate, for each individual, what is beneficial and health-promoting (and appropriate for their community or cultural group) and enables a sense of well-being. The ICF has the potential to help practitioners develop a holistic understanding of the health and functioning experience of Indigenous persons from their perspective [21], is responsive to system and service level complexity and fosters critical reflection and reasoning [22]. This framework has been used successfully in professional education in the region [2,23] and has been recommended in dementia pathways developed locally [24] but, to our knowledge, has not been considered as a formal requirement in policy or service guidelines to structure the critical thinking required in cross-cultural assessments.

Service providers need to seek clarification on what they perceive as cultural expectations or barriers to care. The enhanced physicality of a client's surroundings or implementation of certain care practices may serve to satisfy a non-Indigenous practitioner's concept of cultural accommodation or cultural safety; however, this may be viewed differently by the people receiving support. One of the key concepts underpinning the concept of cultural safety is accepting what the recipients of a service define it to be [25]. The importance of interpersonal relationships is paramount, while gestures like decorative artworks may be regarded as tokenistic [26,27].

Accommodation of personal relationships in a culturally safe way may present the biggest challenge to service providers. It is of critical importance for older people to maintain their cultural and social roles [28] and attend community events, and this goal should be incorporated into models of service delivery. For example, the Yuendumu Old People's Program, developed from many years of sustained community development, incorporates a model of community control where service delivery and quality is defined congruent with local Warlpiri values, kinship systems and cultural practices [27]. A whole-of-community approach to servicing areas of health, food security, safety, housing and transport is better aligned with Indigenous social structures, which again presents challenges to service providers who are still in receipt of 'silo funding' with program guidelines outlining expectations relevant for a more mainstream population. Adopting flexible programs more broadly and legitimising them in revised program guidelines, as well as building the capacity of the health and aged-care workforce to be sensitive to the needs of older Aboriginal people [1], are important steps.

Long-standing problems with staff recruitment and retention in remote communities [29] were clearly described by participants. Cultural standards determine who should be involved in formal and informal care, often based on gender and kin relationships [27]. This may be a limiting factor in providing care for a person with high needs, especially in a small community or one with a fluctuating population. Service users prefer 'countrymen' to perform caregiver roles [9], although some participants in the current study were happy to receive care (or aspects of care) from non-Indigenous staff. If non-local workers were to be introduced or increased in some areas, issues of housing, staff retention and service sustainability would likely arise [17]. Strategies to achieve the goal to increase the number of packages of care available to older Aboriginal people in remote communities [1] need to be multifaceted and financially realistic and involve remote community members in all phases of planning and development. Building the capacity of communities to provide the levels of care required will, over time, limit the current problem occurring whereby resource shortfalls (such as in staffing) mean care packages allocated to communities cannot be accessed by the people assessed as needing them. It may also assist the current problem of older people who are in receipt of a low level of care continuing to receive this level of service even when their needs increase [30].

Conclusion

Aged-care assessments enable access to appropriate community (and residential) care services. Identified needs should be incorporated into a care plan to determine how they are to be actioned. In the challenging context of remote service delivery, disparities often exist between assessment recommendations and service availability. There is also a potential mismatch between Aboriginal understandings of needs, interpretations by individual assessment staff and aged-care program guidelines. A conceptual framework to assist in assessment processes may be required in service guidelines to ensure broad consideration of a person's holistic needs in a structured yet culturally appropriate manner. Additional development work is also required to build the capacity of communities to sustainably provide the level and type of service required by older Aboriginal people and to limit the conditions of hardship many older people and their carers experience, in order to permit them to remain living 'on country'. This was a qualitative study undertaken in central Australia and findings cannot be generalised; however, the key messages may be applicable in many remote aged-care settings. Service delivery for Aboriginal people must occur under the direction of the community itself and be specific to people's values and practices, yet flexible enough to cater for individuals.

Key Points
- Disparities often exist between assessment recommendations and service availability in remote Aboriginal aged care.
- A potential mismatch exists between Aboriginal understandings of needs, interpretations by individual assessment staff, and aged-care program guidelines.
- A conceptual framework to assist in assessment processes may be required in policy and service guidelines, as well as further service development work to build the capacity of communities to provide the levels and types of care required.

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