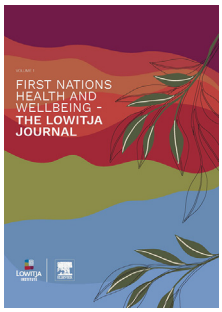

Original Research

Prioritising the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples receiving home-based aged care: An exploratory study

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Abstract

Purpose To explore community and workforce perspectives on how the Home Care Package (HCP) program supports the social and emotional wellbeing (SEWB) of Aboriginal and Torres Strait Islander peoples.

Methods This qualitative design study included semi-structured interviews and a focus group with Aboriginal and Torres Strait Islander peoples receiving an HCP (n = 15) and aged care workers providing service coordination to Aboriginal and Torres Strait Islander peoples (n = 7) across metropolitan, rural and remote areas of South Australia. Semi-structured interviews and the focus group took place between March 2022 and February 2023. Data were analysed using thematic analysis.

Main findings Twenty-two participants were involved in this study. Seven themes representing how the HCP program supports, or could better support, the SEWB of clients were identified: 1) maintaining independence, 2) supporting grief and loss, 3) facilitating social connections, 4) promoting choice and control, 5) assessment and funding, 6) cross-sectoral support and 7) strengthening the workforce.

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Principal conclusions The findings contribute to a deeper understanding of the unique SEWB needs of Aboriginal and Torres Strait Islander peoples accessing home-based aged care services and have significant implications for current and future aged care reforms in Australia.

Keywords: Aboriginal and Torres Strait Islander peoples; Aged care; Home care; Ageing; Social and emotional wellbeing; Quality of life

Highlights

- This study was driven by community-defined priorities and conducted in collaboration with an Aboriginal community-controlled aged care organisation.
- It examined community and workforce perspectives through interviews and focus groups.
- The research findings have significant implications on current and future home-based aged care system reforms.

Introduction

Aboriginal and Torres Strait Islander peoples are living longer and an increasing number of this population are accessing home-based aged care services through the Home Care Package (HCP) program (Australian Bureau of Statistics 2022). As at 31 December 2022, approximately 7,503 Aboriginal and Torres Strait Islander peoples were receiving an HCP across Australia (Australian Institute of Health and Welfare 2023). The HCP program intends to support people to live independently at home by optimising their health and wellbeing in accordance with their needs and preferences, and avoid or delay the need to enter into permanent residential care (Commonwealth of Australia 2021a). There are four HCP levels from Level 1 (low-level needs) to Level 4 (high-level needs) (Commonwealth of Australia 2022). Individuals are assessed for HCP eligibility by an Aged Care Assessment Team (ACAT) of multidisciplinary clinicians. Under the Aged Care Act of 1997 (Commonwealth of Australia 2021a), each person receiving an HCP has the right to safe and high-quality services, be informed about their services, and have their personal needs, identity and culture supported (Australian Government 2021). The range of services funded under the HCP program include those that aim to keep people well, safe and connected to their community (Commonwealth of Australia 2021a).

Home-based aged care services are delivered using a consumer-directed care (CDC) model (Day et al. 2018), which aims to empower consumers to choose the type of support they would like to receive, who delivers this support, and when and where it is delivered. However, several concerns of CDC relating to Aboriginal and Torres Strait Islander peoples have been raised (Australian Association of Gerontology 2017; Davis 2019; Ottmann 2018), including: the exclusion of family, community, culture and Country within care, the lack of service connectivity for those with multiple and compounding needs and it overlooks the significant barriers that Aboriginal and Torres Strait Islander peoples face in accessing services (Australian Association of Gerontology 2017; Davis 2019; Ottmann 2018).

The Royal Commission into Aged Care Quality and Safety (2021), the culmination of extensive inquiries and reforms to the Australian aged care sector, has

identified major shortcomings of the aged care system in adequately supporting the culturally specific health and wellbeing needs of Aboriginal and Torres Strait Islander peoples (Commonwealth of Australia 2019, 2021b). For Aboriginal and Torres Strait Islander peoples, health is a holistic concept that encompasses the social, emotional, spiritual and cultural health and wellbeing of the person and their community, including unique experiences of grief and loss (Gee et al. 2014). The term social and emotional wellbeing (SEWB) has been adopted to reflect this definition of health (Gee et al. 2014). The grief and loss experienced by Aboriginal and Torres Strait Islander peoples stems from the forcible removal of children from their families, and the loss of land, language and ability to maintain cultural practices (Wynne-Jones 2016). The historical and ongoing processes of colonisation continues to significantly impact the SEWB of Aboriginal and Torres Strait Islander peoples (Wynne-Jones 2016). Aboriginal and Torres Strait Islander peoples have advocated for greater understanding and application of SEWB embedded throughout the aged care services they receive (Gibson et al. 2020). In this study of 16 Aboriginal and Torres Strait Islander peoples, participants perceived some service providers as discriminatory, non-responsive to their SEWB needs, and prioritising their employer's needs rather than their clients' needs (Gibson et al. 2020).

Understanding of Aboriginal and Torres Strait Islander peoples' wellbeing has been uniquely characterised through a strong sense of interconnectedness, and important connections such as communities, families and kinship ties are often prioritised over the needs of individuals (Butler et al. 2019). Quality of life and wellbeing models are increasingly being explored in older populations. A study of 56 older Aboriginal peoples aged ≥ 45 years identified that wellbeing and 'having a good spirit and life' in older age was supported by a relational model of care called Good Spirit, Good Life (GSGL) (Smith et al. 2021). This approach involves supporting connections to a range of interconnected factors including culture, friends and family, health and spirituality (Smith et al. 2021). Older Aboriginal peoples with strong connections to the GSGL factors are less likely to experience anxiety and depression (Gilchrist et al. 2023). Adding to the evidence base is a recent culturally and psychometrically designed and validated measure of wellbeing for Aboriginal and Torres Strait Islander adults: the What Matters to Adults (WM2A). The WM2A includes most adults aged ≥ 45 years (Howard et al. 2024) and has 32 interconnected wellbeing indicators across 10 domains (Garvey et al. 2021; Howard et al. 2024) with several common domains to the GSGL.

Adding to the urgency for safe and quality care is that, as of 2023, all survivors of the Stolen Generation were aged ≥ 50 years and potentially eligible for aged care services (The Healing Foundation 2019a). Stolen Generation survivors are Aboriginal and Torres Strait Islander peoples who were forcibly removed as children from their families and communities through race-based policies between 1910 and the 1970s (The Healing Foundation 2019b). It is estimated that one in four Aboriginal and Torres Strait Islander peoples aged ≥ 50 years are Stolen Generation survivors (Australian Institute of Health and Welfare 2021). The grief and loss experienced by Stolen Generation survivors, their families and communities have impacted multiple generations of Aboriginal and Torres Strait Islander peoples. Many Stolen Generation survivors experience complex trauma and require additional case management support to assist them (The Healing Foundation 2019b).

A growing body of research has sought to understand the needs of Aboriginal and Torres Strait Islander

peoples in aged care (Brooke 2011; Deravin et al. 2023; Gibson et al. 2020; Parrella et al. 2021; Sivertsen et al. 2019, 2020; Thomas et al. 2023). However, these studies have not specifically focused on how the HCP program, or home-based aged care more broadly, meets the SEWB of Aboriginal and Torres Strait Islander peoples. This study aimed to explore how the HCP program supports the SEWB of older Aboriginal and Torres Strait Islander peoples from the perspective of both Aboriginal and Torres Strait Islander peoples receiving an HCP and the HCP workforce.

Methods

Design

This study was proposed by the Chief Executive Officer (CEO) of Aboriginal Community Services (ACS), a South Australian Aboriginal community-controlled aged care organisation (Aboriginal Community Services 2023), to understand how the HCP program is meeting the needs of Aboriginal and Torres Strait Islander peoples and what is required to support the workforce in meeting those needs. This study was collaboratively designed by ACS and Wardliparingga Aboriginal Health Equity at the South Australian Health and Medical Research Institute (SAHMRI).

Ethics and governance

Approval was provided by the Australian Institute of Aboriginal and Torres Strait Islander Studies Research Ethics Committee (#EO279-20210726) and the South Australian Aboriginal Health Research Ethics Committee (#04-21-971). This study was conducted in accordance with the South Australian Aboriginal Health Research Accord (Morey et al. 2023; South Australian Health and Medical Research Institute 2014) and under the guidance of a study advisory group, which included a majority of Aboriginal and/or Torres Strait Islander community members, service providers and health and aged care researchers. The study advisory group was involved in data collection and analysis, and dissemination of the research findings.

Recruitment

Community members were recruited from a stratified, randomised sample of eligible clients who were receiving HCP services through ACS. The following inclusion criteria applied: Aboriginal and Torres Strait Islander peoples aged ≥ 50 years who were receiving HCP services through ACS and had the ability to provide informed consent. A de-identified list of eligible clients was collated by an ACS employee who was independent of the SAHMRI researchers and not involved in coordinating HCP services. This list contained the following information: HCP ID, self-identified representation of gender identity, date of birth, postcode, HCP start date, HCP level and approved HCP level. The de-identified list was provided to the SAHMRI researchers for randomisation, using Excel (Microsoft Corporation 2018). Potential participants who were randomly selected were mailed a study invitation letter, participant information statement and consent form from the ACS staff member.

The HCP service coordinators were recruited through a purposive sampling strategy (Walter 2019). The CEO of ACS on behalf of the research team provided the HCP coordinators with study information, which included a letter of invitation, participant information sheet and consent form. The CEO of ACS endorsed support for staff to participate in the focus group and/or interview during work hours.

Informed consent was confirmed by a researcher prior to the interview or focus group by verifying participants' understanding of the study purpose and involvement. Participants then signed a consent form.

Data collection

Semi-structured interviews with community members took place between March 2022 and February 2023 (JZ, MD, AP). Interviews were conducted either face-to-face, by phone or videoconference, according to participant preference. An interview guide informed by the SEWB model of Gee et al. (2014) and the Aboriginal designed and validated quality of life tool for older Aboriginal peoples (GSGL) was used (Gilchrist et al. 2023; Smith et al. 2021). The open-ended questions related to the domains of each model and covered two overarching topics: 1) how the services and items funded through their HCP supported SEWB and 2) how the HCP workforce could best support their needs.

A focus group was held with HCP coordinators in April 2022 (OP, AP, JZ, MD). A discussion guide consisting of three topics was used to direct the focus group and interview and included: 1) enablers and/or barriers to supporting the SEWB of clients, 2) adequacy of the HCP funding rules in supporting the SEWB of clients, and 3) training, resources and professional development needs. Findings from the third topic are reported elsewhere (Parrella et al. 2024). The focus group consisted of a breakout session, where coordinators collectively handwrote their responses to the above topics. This was followed by an open-ended roundtable discussion to further explore their written responses. For coordinators who could not attend the focus group, a semi-structured interview was conducted using the same discussion guide (JZ, MD).

With participant consent, all interview and focus group data were audio recorded and transcribed verbatim by a third-party transcription service. The written responses were collected and scribed verbatim. Each participant was offered a copy of their transcript.

Demographics	HCP clients (*n* = 15)
Gender	
Men	7
Women	8
Location	
Metropolitan	6
Rural	5
Remote	4
Age in years, mean (range)	66.8 (52 – 83)
Current HCP level	
Level 1	–
Level 2	7
Level 3	6
Level 4	2
Years on HCP, mean (range)	2.1 (0.58 – 4.75)

Table 1: Demographics of community members receiving a Home Care Package

Data analysis

The interview and focus group transcripts were read and de-identified using alpha-numeric codes to protect the anonymity of participants. Using NVivo V.20 (QSR International Pty Ltd 2022), the transcripts were thematically analysed using an inductive approach (JZ, MD, AP) (Braun & Clarke 2006). Written responses were also scanned and imported into NVivo V.20 for analyses. Initial codes were generated and then subthemes and themes were formed by collating similar codes together. The Study Advisory Group met four times during data analysis, providing their input on the themes based on the data. Summary results were sent to participants and subsequently contacted by the researchers for feedback; this occurred via phone calls with community members (JZ) and through a validation workshop with HCP coordinators in February 2023 (OP, AP, JZ).

Results

Demographics

Fourteen interviews were conducted with 15 community members (Table 1) and a focus group and interview with seven HCP coordinators (four females,

three males), who were providing services across metropolitan (*n* = 5) and rural (*n* = 2) South Australia. Three coordinators identified as Aboriginal and/or Torres Strait Islander people.

Interview times ranged from 23 minutes to 1 hour and 54 minutes and the focus group approximately 3 hours. Seven themes emerged that represented how the HCP program supports, or could better support, the SEWB of Aboriginal and Torres Strait Islander peoples: 1) maintaining independence, 2) supporting grief and loss, 3) facilitating social connections, 4) promoting choice and control, 5) assessment and funding, 6) cross-sectoral support and 7) strengthening the workforce. Themes and associated illustrative quotes are presented in Table 2.

Maintaining independence

Community members expressed wanting to maintain their independence for as long as possible. Many described that the services and items they were receiving to support their physical and domestic needs were able to support them to live independently at home, which to some extent positively impacted SEWB. This sentiment was shared by the coordinators, who described a range of services and items, including white goods, cleaning and gardening, to support their clients' independence, of which they also considered integral to SEWB. Community members described their happiness when they were able to identify what they needed to support their independence, and when their coordinator was proactive in organising it for them. However, some community members expressed hesitancy and shame in accessing services that would support their independence, which negatively impacted their SEWB. The reluctance to seek support stemmed from their fear of being judged by non-Indigenous peoples.

Supporting grief and loss

Community members recounted past and recent loss of family and community members. The way in which they spoke of their grief and loss varied. Some described isolating themselves from community or activities they enjoyed, others described wanting to participate in social activities within their community to address their feelings of loneliness and isolation. Most spoke about the healing effect that Country would or could have on their grief and loss. Some were able to draw upon their HCP funding to attend Sorry Business but this was not consistent. No community member spoke of dedicated SEWB services they were accessing through their HCP and identified the need for additional support for their grief and loss within the HCP.

Facilitating social connections

Community members valued the opportunity to spend time with family, friends and the broader community, and described these connections as significant to their SEWB and believed that they should be able to access funding through their HCP to do so. Reflecting that many of their clients were socially isolated, coordinators discussed that social groups help maintain a sense of community, and that this was particularly important for Stolen Generation survivors. Additionally, the coordinators believed that many of their clients preferred to yarn with other community members for support rather than seeking formal support through mental health clinicians. Given that a key objective of the HCP program is to meet wellbeing needs, all participants believed that facilitating social connections should be better embedded within HCP funding arrangements. Funding and resourcing constraints were considered barriers to facilitating access to social activities within HCP funding.

Theme	Illustrative quote
1. Maintaining independence	
1a. HCP supporting independence	It was good because I couldn't walk or anything. I had a girl come to take me shopping and done a bit of house cleaning and a few things like that. No, it was excellent… I know if they weren't around, I wouldn't be here – Community member, 13
2a. Independence integral to SEWB	Social and emotional wellbeing is a very, very big part of what we're out to achieve… keeping them in their homes longer, where they're comfortable and with all the appropriate equipment and all that kind of stuff – Coordinator, 7
3a. Shame around accessing services	When they told me about this [Home Care Package], I think 'Oh, I don't like doing that', you know? Because you get labelled… I've heard people – white people – saying, 'Oh, you black fellas get this, you get that' – Community member, 1
2. Supporting grief and loss	
2a. The experiences of grief and loss	When my husband first died, I used to catch a cab over to [shopping centre] at quarter to 10 every morning. I'd get my takeaway coffee. I'd sit in my walker at the back of the chemist all day just watching people go past. Then I'd catch a taxi home at quarter to five, because I couldn't stand being in the house by myself – Community member, 8
2b. The healing effects of Country on grief and loss	I feel so much better when I'm on the Country where I'm from and being with my families… It's just a rejuvenation period that I kind of absorb, and I come back, and I feel much better and healthier and much better within myself as well, which is a good feeling – Community member, 7
2c. More support required for grief and loss	Offering a card for a petrol voucher or offering a card to help out with food, just showing some kind of support because that's at the root of all our problems. We're not only grieving for deaths, but we're also grieving for the loss of our culture, Country… It's still inbuilt in us… grief is a big part of our health and wellbeing. If that's not addressed, then you just see us go downhill with our health – Community member, 4
3. Facilitating social connections	
3a. The need for social activities and connections to be embedded throughout funding	I do, because it's a cultural thing and we need to have that cultural contact with our local people… it just rejuvenates us in inside as well. That's a real big bonus for me as well – Community member, 7 Elders are screaming out for social activities. They are screaming out just to get back together and sit in a group and have a coffee, just to have a chat… and 99.995% of the time, they won't talk to anybody else. They're not going to go to a counsellor to support their emotional wellbeing… So this is why so much I want to get this social stuff up and going – Coordinator, 6
3b. Barriers to accessing social activities	Social events or going out on an outing… Mixing with other people would be good… Just having a yarn while we're painting or sewing, or even cooking classes. Maybe each month they change the activities where we could go, but I guess it all costs money. I think that's the thing that [providers] worry about – Community member, 11
4. Promoting choice and control	
4a. Difficulties in navigating funding rules	Things like inclusions and exclusions, which we cannot – we try and stretch things as much as we can. But when it comes down to it, if we can't make that purchase, we can't make that purchase – Coordinator, 2
4b. The need for increased flexibility	We need to have more say on what we can spend our funds on, and it needs to be to each individual person's needs… it's our money and if we're not being stupid with it, I can't see why we can't get what we need to make our life comfortable. So, it's like being dictated to us like back in the old missionary days, come and get your rations – Community member, 4
4c. Choice and control impacted by inappropriate communication	[My Aged Care] spend thousands of dollars on paying people to construct these wonderfully helpful letters that mean absolutely bugger all to the people they go to. They're just confusing so I do what most people do which is fold them in half and then I ring up [aged care coordinator]… It's not to say people are silly. It's that level of speak that comes out of Canberra and the policies that you're required to use doesn't have a lot of meaning for the people on the receiving end – Community member, 6
5. Assessment and funding	
5a. Lower-level packages insufficient	Their basic needs are real, and you cannot fulfil all their basic needs, not on a level one or two – Coordinator, 6 That's just the [ACAT's] assumption… How do you look at an 89-year-old lady, arthritis, a hip replacement, can't do her own dishes, can't make her own bed… and they put her on a level one? That's a level three/four minimum… That just accounted for her diet alone, and then her money was gone. How do they come up with these numbers? – Coordinator, 7
5b. Culturally inappropriate assessments	There's no Aboriginal-specific support in regard to ACAT assessments… To have that understanding, culturally, there's only a handful, I believe, of people that would even work in the ACAT team that are either Indigenous themselves or have a good understanding of the cultural community – Coordinator, 2

(Table 2 continues on next page)

Theme	Illustrative quote
(Continued from previous page)	
5c. Holistic ACAT assessments are required	I'd make sure that there's an assessment on social isolation or social wellbeing and stuff like that. Cultural activities or cultural connections... and cultural engagement... A big picture of social interaction, health and social and wellbeing and cultural and stuff like that... A big picture of everything – Community member, 3
6. Cross-sectoral support	
6a. Need for cross-sectoral support	They have their aged care but they need support with the health, their housing. But they don't know where to go for these services – Community member, 14
6b. Going outside scope of practice	I've had to help with bills and I've had to help with housing and help with – goodness, take them shopping. I go out of my scope every day because there's somebody that needs some help and there's nobody else to help them – Coordinator, 1
6c. Siloed nature of health and aged care	We all have a common goal and the agencies don't work together to meet that. It's like, you're on your own, they've got a package, they're yours, you deal with it – Coordinator, 4
7. Strengthening the workforce	
7a. Importance of Aboriginal workforce	I mean, some of the coordinators are Indigenous themselves, so they can completely understand. They talk just like that we're family together when they see us... which is great. That's a real big help too, because there's a lot of communication problems with some of the other providers – Community member, 7
7b. Aboriginal workforce supporting SEWB	It's also culturally appropriate... One is an Elder and he's a lawman in the community so he's very well accepted. So, they have that cultural – so, they can go to people's houses and... people will open up to them about things that they would never speak to us about. So, that helps us get a better understanding of the clients and how we can support them – Coordinator, 2

Table 2: Themes with illustrative quotes

Promoting choice and control

Coordinators described the primary function of the HCP program as a way to keep a person living safely at home, and because of this they felt as though they were required to prioritise clinical services and domestic assistance, or what they determined was a 'need' for their client. These priorities were sometimes different to those of their clients, who often prioritised home maintenance and social and cultural connections. Social and cultural connections were considered a 'want' by the funding rules and while coordinators attempted to promote client choice as much as possible, they had to defer to the funding rules. However, having a strong connection with culture and community was integral to community members' SEWB. They spoke of the need for flexibility in funding to access cultural activities, including returning to Country, whenever possible to support them. As a result, coordinators spent significant time interpreting and navigating the funding rules to promote choice and control and effectively meet the SEWB of their clients.

Community members agreed that while rules should be in place, to truly exercise choice and control they should have access to a broader range of services than what was being offered to them. Further impacting the ability to exercise choice and control was community members' difficulties in understanding much of the language used in communication from My Aged Care, the main entry point for accessing Australian government-funded aged care services and information available online, in person or over the phone (Commonwealth of Australia 2023).

Assessment and funding

Community members and aged care coordinators felt as though assigned HCP levels were, at times, not commensurate to need. Coordinators believed that HCP funding should comprehensively address all of their clients' needs; however, they described it as difficult to do so when clients had greater needs than their HCP could provide for. This was evident with lower-level packages (e.g. Level 1 or 2) due to the

limited amount of funding and the often-complex care requirements. Coordinators described that it became increasingly difficult to meet the cultural needs of clients unless they were receiving a high-level package. This was also emphasised by community members, who described difficulty in accessing services due to the limited funding available to them and were therefore required to 'save up' for much needed items. Both community members and coordinators identified that the mismatch of allocated funding levels was due to culturally inappropriate aged care assessments that were not conducive to the needs and preferences of Aboriginal and Torres Strait Islander peoples. While an ACAT assessment took into consideration medical needs, community members and coordinators alike felt that it needed to better capture social and cultural needs.

Cross-sectoral support

The coordinators talked of how it was common for clients—many of whom lived with complex physical, social, wellbeing and cultural needs—to receive support and services beyond their HCP; this included public housing, health and welfare. Community members often spoke to their coordinator about the difficulties they faced in navigating these services by themselves and often requested support. Navigating these services on behalf of the client proved difficult for coordinators, and despite being outside their scope of practice, they wanted to ensure that their client was receiving continuous and comprehensive support and would spend significant time advocating and accessing other services. These services operated in 'silos' and did not accommodate for the complexities associated with service delivery across health and aged care services. Another difficulty was that once approved for a HCP, other government funded services that a person was receiving would stop without any consideration of individual circumstances or the approved level of funding.

Strengthening the workforce

The need to employ more Aboriginal and Torres Strait Islander peoples throughout HCP services was a common discussion. At times, clients felt safer with an Aboriginal and/or Torres Strait Islander worker who they saw as being able to better understand and respect cultural protocols and practices. The coordinators also considered the Aboriginal workforce employed within their organisation as integral to supporting SEWB. A second suggestion was that whether Aboriginal or non-Aboriginal, the aged care workforce needed to expand their knowledge in areas including, but not limited to, SEWB, grief and loss, dementia and trauma-informed care. Coordinators experienced difficulties in accessing training in these areas and believed that it should be a responsibility of their employer to provide them with adequate opportunities to upskill. Community members emphasised the need for the aged care workforce to have more support to be able to individualise the services they were providing. Additionally, community members valued workers who had a strong understanding of their SEWB needs. Although there were variations in understanding what SEWB meant to their clients, on the whole, all coordinators agreed that having a strong connection to culture and Country was central.

Discussion

It is believed that this is the first study to explore how the HCP program, or home-based aged care, supports the SEWB of Aboriginal and Torres Strait Islander peoples. The seven identified themes highlight enablers and barriers across HCP service delivery and policy in prioritising the SEWB of Aboriginal and Torres Strait Islander peoples within the HCP program (Gee et al. 2014), including the domains significant to wellbeing identified within the GSGL tool (Smith et al. 2021) and the WM2A wellbeing measure (Howard et al. 2024). Broadly, this study reinforces the tensions that

exist between CDC models and service provision for Aboriginal and Torres Strait Islander peoples identified within the literature (Australian Association of Gerontology 2017; Davis 2019; Ottmann 2018), including emphasis on the individual to the exclusion of community, culture and Country, and the lack of service connectivity. This has resulted in significant barriers to ensuring that HCP service delivery is grounded within culture.

The focus of the aged care system on physical health (Sivertsen et al. 2019) overlooks the values significant to Aboriginal and Torres Strait Islander peoples. In this study, external factors to immediate physical needs, such as social and cultural connections, were equally important to SEWB. For Aboriginal and Torres Strait Islander peoples, the HCP program must view wellbeing in a holistic way that encompasses physical health, and mental, cultural and spiritual health. The aged care system must recognise that when the interaction of these elements is disrupted, attempts to promote wellness, reablement and independence, which are key elements of the HCP program, will likely fail (Commonwealth of Australia 2021a; National Aboriginal and Torres Strait Islander Ageing and Aged Care Council 2020).

The Aged Care Royal Commission has recommended that residential aged care providers make funds available for Aboriginal and Torres Strait Islander peoples to retain connection to Country, including meeting the costs of travel to and from or providing infrastructure such as videoconferencing technology (Commonwealth of Australia 2021b). However, the current findings show that this is equally important to those receiving services at home. While some community members had the opportunity to use their funds to connect with Country, this was usually to the detriment of other services or items they needed. Hence, this recommendation (which was accepted by the Commonwealth in 2021) should extend to home-based services and not to the detriment of the quality of services elsewhere from their package.

The findings of this study have also highlighted the lack of choice and control Aboriginal and Torres Strait Islander peoples have over how they use their funding, significantly impacting upon SEWB. Self-determination, critical to improving the health outcomes of Aboriginal and Torres Strait Islander peoples, should be a key element in the provision of aged care (National Advisory Group for Aboriginal and Torres Strait Islander Aged Care 2020). This study found that in order to be self-determining, or have choice and control, access to clear information was paramount. This would enable Aboriginal and Torres Strait Islander peoples to manage their needs in a way that is more appropriate. There is therefore an ongoing need to promote choice and control through appropriate communication mechanisms that are based on individual needs and circumstances, and that provide clear and consistent messaging for people to know where to access information about the variety of services available to them.

Many of the services and items that were denied, or which required significant effort to be approved, included social support, food security and home modifications to public housing. These needs were largely overlooked because of inflexible funding rules, which defined the range and scope of funding. However, the reality for many community members was that the services and items they were accessing were insufficiently supporting their SEWB in a way that was most meaningful to them. Such examples point to a need to review how the aged care system can be better integrated with broader health and human services to adequately address the social

determinants of health and wellbeing in aged care (Pearson et al. 2020).

The aged care assessment experiences referred to in this study reflect a culturally unsafe environment identified within the literature (Aboriginal and Torres Strait Islander Ageing Advisory Group 2020; Australian Association of Gerontology & Aboriginal and Torres Strait Islander Ageing Advisory Group 2019). Study participants believed that this resulted in assessment decisions that did not accommodate peoples' needs. It is therefore essential to use culturally informed aged care assessment tools, such as the GSGL (Smith et al. 2021), to be able to address SEWB needs. As part of ongoing reforms across the sector, new quality indicators (QI) will be developed for aged care providers to be led by (Commonwealth of Australia 2021b). One of these QIs will concern quality of life; therefore, culturally informed assessments will be significant upon entering aged care and also throughout ongoing care provision.

These findings are significant, given that Stolen Generation survivors now represent the cohort entering the aged care system. Supporting Aboriginal and Torres Strait Islander peoples to enjoy high levels of SEWB is a national priority (Cox et al. 2023). The Australian Government will introduce the Support at Home Program in July 2025, which is a new aged care program that merges and replaces the current home-based aged care options, including HCPs (Commonwealth of Australia 2021b). It is essential that the needs of Stolen Generation survivors are carefully and appropriately considered in the design and delivery of this new program, and dedicated SEWB support made readily available to ensure that entering the aged care system does not perpetuate experiences of trauma for this cohort.

Strengths and limitations

A strength of this study was that it was informed by frameworks developed by and with Aboriginal and Torres Strait Islander peoples (Gee et al. 2014; Smith et al. 2021). This ensured that Aboriginal and Torres Strait Islander concepts of health and wellbeing have been embedded and reflected throughout each stage of the research. This study has built upon existing collaborations driven by community defined priorities. Furthermore, having participants endorse the research findings enabled confidence in the validity of findings. Limitations of this study included the small sample size; however, there was diversity in gender, age and geographical location.

Conclusions

These findings will inform service delivery for the workforce to better meet the expressed needs of their clients and provide clear evidence to aged care policymakers on how the HCP program can meet the SEWB needs of Aboriginal and Torres Strait Islander peoples. Purposefully including insights of Aboriginal and Torres Strait Islander cultural ways of being and doing and a specific focus on the structural drivers of inequity in access, health and social outcomes burdened by this population group may contribute to effectively caring for the additional unique SEWB needs of Aboriginal and Torres Strait Islander consumers of aged care. Prioritising and protecting the SEWB of Aboriginal and Torres Strait Islander peoples as they age is critical to the prosperity and cultural continuity of communities. The SEWB of Aboriginal and Torres Strait Islander peoples is intrinsically linked to living a long and healthy life, and the ability of older people to meaningfully participate and contribute to the social fabric of their communities. This places great importance on the need for high-quality home-based aged care services that meet the SEWB needs of Aboriginal and Torres Strait Islander peoples.

Author contributions

This study was collaboratively designed and conducted by GA, AB, OP and AP, including funding acquisition. Recruitment and data collection were undertaken by JZ, AP, OP, MD and TI. Data analysis was undertaken by JZ, MD, AP, OP, with TB, MW, KS and TI providing guidance and input. Validation of research findings was undertaken by OP, AP and JZ. The original draft of this manuscript was written by JZ. OP, MD, TB, KS, MW, TI, GA, AB and AP all contributed to providing feedback and writing. All authors have read and agreed to the published version of this manuscript.

Data sharing

Data from this study are not available due to the sensitive nature of the content discussed.

Declaration of interests

Graham Aitken is the Chief Executive Officer of Aboriginal Community Services and Chief Investigator on this project. To mitigate this potential conflict of interest he was not involved in data collection or analysis. Odette Pearson reports that financial support was provided by the Australian Institute of Aboriginal and Torres Strait Islander Studies. Graham Aitken reports that financial support was provided by the Australian Institute of Aboriginal and Torres Strait Islander Studies. Alex Brown reports that financial support was provided by the Australian Institute of Aboriginal and Torres Strait Islander Studies. Adriana Parrella reports that financial support was provided by the Australian Institute of Aboriginal and Torres Strait Islander Studies. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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