A qualitative exploration of the non-financial costs of cancer care for Aboriginal and Torres Strait Islander Australians

Rachel Cummins,[1,†] Robyn Preston,[2,3]* Stephanie M. Topp,[4] Judy Taylor,[3] Sarah Larkins,[3] Emily Callander,[5,6] Lorraine Bell,[7,8] Brian Arley,[9] Gail Garvey[7,10]

[1]Djiru/Jirrabal/Bwgcolman, College of Medicine and Dentistry, Bebegu Yumba, James Cook University, Townsville, Australia

[2]Public Health, College of Science and Sustainability, School of Health, Medical and Applied Sciences, CQUniversity, Townsville, Australia

[3]College of Medicine and Dentistry, James Cook University, Townsville, Australia

[4]College of Public Health, Medical and Veterinary Sciences, James Cook University, Townsville, Australia

[5]Monash University, School of Public Health and Preventive Medicine, Melbourne, VIC 3004, Australia

[6]Health Services Management, University of Technology Sydney, School of Public Health, Sydney, Australia

[7]Menzies School of Health Research, Darwin, Northern Territory, Australia

[8]Australian e-Health Research Centre CSIRO, Brisbane, Queensland, Australia

[9]Daru, Tudugal, Menzies School of Health Research, Charles Darwin University, Darwin, Australia

[10]School of Public Health, Faculty of Medicine, The University of Queensland, Darwin, Australia

Abstract

Objective: Knowledge is growing about cancer care and financial costs for Aboriginal and Torres Strait Islander people. However, much remains unknown about the true costs of cancer care, encompassing financial, emotional, and spiritual aspects. We aimed to explore and explain how non-financial costs affect the health-seeking behaviours of these clients.

Methods: Following Indigenous research protocols, this research was led by Aboriginal and Torres Strait Islander researchers and guided by Indigenous Hospital Liaison Officers. In-depth interviews and focus groups were conducted with 29 participants (Aboriginal and Torres Strait Islander cancer clients, their carers, and cancer-care professionals) at two Queensland public hospitals.

Results: Four interwoven themes encompass non-financial costs of healthcare: leaving home and family; loss of control during cancer treatment; health of the spirit; social costs. The Aboriginal relational concept of 'being held' is useful in considering client, family, and carer as central to care with the Indigenous Hospital Liaison Officer two-way interpreting between the care and client team.

Implications for Public Health: Framing the reasons that clients and carers have difficulty in engaging in treatment as 'costs' enables a focus on how the health system itself is implicated in the disengagement of Aboriginal and Torres Strait Islander clients from treatment.

Keywords: Aboriginal and Torres Strait Islander, cancer, out of pocket costs, social costs, barriers to care

Introduction

Clear and increasing disparities exist in the burden of cancer, between Aboriginal and Torres Strait Islander Australians and non-Indigenous Australians.[1] Aboriginal and Torres Strait Islander Australians have higher overall cancer incidence, mortality rates, and poorer survival than that of non-Indigenous Australians.[2] Efforts to reduce the disparity in cancer outcomes have largely focused on addressing lower cancer screening rates, lower treatment uptake, poorer access to health services and understanding Aboriginal and Torres Strait Islander clients' experiences of care.[3] Aboriginal and Torres Strait Islander peoples' engagement with cancer services and treatment occur within a broader historical, socio-political, and economic context.[4,5] The social determinants of health (e.g., poverty and lack of a culturally responsive health system) contribute to the cancer burden faced by Aboriginal and Torres Strait Islander peoples.[6] Understanding Aboriginal and Torres Strait Islander peoples' engagement with health services and cancer care must also consider the contexts in which health care is delivered. The Australian health system is based on a biomedical and pathology-based approach to health and is devoid of Aboriginal and Torres Strait Islander concepts

of health and wellness that extend beyond the disease and the physical wellbeing of an individual.[7] In Australia's state-based health services, disparities in cancer outcomes amongst Aboriginal and Torres Strait Islander Australians reflect decisions about service design that inhibit both initial access and long-term engagement, for example, the physical location of specialist services in larger cities, and the increasing move towards more centralised models of service delivery. Experiential (deidenitified name of first author and name of traditional ownership groups and lead researcher) and empirical evidence[8] show that some Indigenous people who live remote from major hospitals do not present to hospitals until seriously ill.

For Aboriginal and Torres Strait Islander peoples, health is a holistic concept that applies to both individual and community; recognises the social, emotional, cultural, colonial, spiritual, ecological as well as biophysical determinants; emphasises the connectedness amongst all these factors.[9] Research spanning the past decade has continually documented how tensions between this holistic understanding of health on the one hand, and the biomedical culture of public or 'mainstream' health services on the other, result in barriers to cancer treatment for Indigenous Australians across physical, logistical, psychosocial, and cultural dimensions.[10–14]

Client experience is recognised as a major aspect of healthcare quality and safety and understanding those experiences is increasingly promoted as central to improving service and health outcomes.[15] Evidence on the care experiences of Aboriginal and Torres Strait Islander cancer clients has grown over the years and reflects a system fraught with many challenges. For example, there is a scarcity of Indigenous care providers and staff in cancer services; many Indigenous clients face challenges associated with language, and practical needs such as accommodation, transport, and financial support; being dislocated from home; as well as experience disjointed and fraught relationships with care providers which may result in delayed commencement of treatment.[16,17] Interwoven with systemic racism throughout the mainstream state health system,[18] it is the persistence of the deficit model of Aboriginal and Torres Strait Islander Australians' health. Furthermore, the inability to recognise the knowledge and the centrality of relationships and culture for Aboriginal and Torres Strait Islander people that are impediments in accessing care.[19]

While the cost of treatment is a well-recognised dimension of treatment access, it has typically been examined using quantitative methods that make assumptions regarding how those costs impact patient experience and also which costs actually matter the most.[20] Studies of the cost of cancer care have almost exclusively focused on out-of-pocket financial costs. One recent study conducted in Queensland on the out-of-pocket costs for cancer care highlighted that although Indigenous Australians with cancer had lower out-of-pocket expenditure than non-Indigenous Australians, they also accessed fewer Medicare services including specialist attendances, pathology tests, and diagnostic imaging.[21]

Given the growing understanding of the multi-dimensional impacts of service design on treatment access and engagement, there is need for greater reflection around the holistic understanding of health for Aboriginal and Torres Strait Islander Australians[22] that takes into account all the costs of cancer treatment that go far beyond the financial.

Nested within a broader program of work seeking to quantify and understand cancer care costs, this multi-site qualitative study sought to gain an in-depth understanding of the non-financial costs incurred by Aboriginal and Torres Strait Islanders accessing cancer care consistent with their holistic understanding of health. This research aimed to explore how the non-financial costs associated with cancer affect the health-seeking decisions and behaviours of Aboriginal and Torres Strait Islander cancer clients and their families. In recognition of Aboriginal and Torres Strait Islander Australians communities' holistic understandings of health, the study takes a broad definition of 'cost', as understood by the participants and consciously incorporates non-financial costs, such as social, psychological and spiritual costs of cancer. From a public health perspective, hearing the voices of Aboriginal and Torres Strait Islander people who have experienced cancer may assist in addressing, in practice and policy cancer inequities.

Methods

This project was underpinned by the core principles of leadership of Aboriginal and Torres Strait Islander researchers and privileging and prioritising the voices of Aboriginal and Torres Strait Islander researchers, stakeholders, clients, and Indigenous Hospital Liaison Officers (IHLOs) throughout the study.[23,24] The engagement of and role of the Indigenous Women's Cancer Coordinators at the study sites were crucial for data collection and analysis.

Ethical approval was received from the [Local ethical review details blinded for peer review] Human Research Ethics Committee and site-specific approval from [deidentified hospital and health service] and [deidentified hospital and health service].

Sampling and Recruitment

The study was conducted at two large tertiary hospitals in Queensland, Australia, one in a metropolitan area and the other in a regional area. We sought interviews with three groups of key informants: (i) Aboriginal and Torres Strait Islanders currently receiving outpatient cancer treatment (clients); (ii) primary carers of Aboriginal and Torres Strait Islanders receiving cancer treatment; (iii) clinical and allied health professionals or employees of non-government organisations involved in cancer service delivery to Aboriginal and Torres Strait Islanders. Sampling of clients, health workers and community sector representatives was purposive and opportunistic.

Participant (clients and primary caregivers) recruitment was conducted similarly at the two sites by Aboriginal and Torres Strait Islander Research Officers (deidentified initials of first and eight author). They worked with the IHLOs and cancer staff at each participating cancer centre. Participant recruitment would have been enhanced by an improved information flow and support for the study at all levels within the hospitals. In addition, identifying Aboriginal or Torres Strait Islander cancer clients was challenging because client information did not always identify whether people were Aboriginal or Torres Strait Islander.

Recruitment of clinical and allied health professionals or employees of non-government organisations occurred through pre-arranged site visits and email communication by members of the investigator team.

Data Collection

Interviews or focus group discussions with clients and their carers were conducted by Aboriginal and Torres Strait Islander researchers (deidentified initials of first and eight author) and interviews with service providers were undertaken by either an Aboriginal or Torres Strait Islander (deidentified initials of first and eight author) or non-Indigenous (deidentified initials of second and fourth author) researchers.

Interviewing Aboriginal or Torres Strait Islander clients demanded trusting relationships between the interviewers and the participant that took time to build and often interviews were obtained because of existing relationship networks. Different approaches were necessary for interviewing participants of different genders. Interviews were conducted at a time and location convenient to the participant, usually in their home.

A study information sheet was reviewed by the participant and written consent was obtained prior to commencement of the interview. The semi-structured interviews were guided by open ended questions whilst enabling emergent themes to be probed and explored by the investigators (Supplementary Material 1 interview guides). Interview guides were developed and piloted with potential participants prior to use. All interactions were audio-recorded with the participants' consent or notes taken. The interviews varied in length from 20 minutes to one hour and the audio recordings were transcribed verbatim.

Data Analysis

Data was analysed following an Aboriginal and Torres Strait Islander approach led by (deidentified initials of first author) [24].All qualitative data were stored electronically in password-protected computers. Interview transcripts were read and re-read by three authors (deidentified initials of first, second, and fourth author) and codes were developed inductively as we learnt about the story being told. All data, using these codes, were entered into NVivo 12 Plus (QSR International 2018) (deidentified initials of fourth author) and data allocation to codes checked by [deidentified initials second author] and [deidentified initials first author] and discussed where there were discrepancies. Coded data were re-examined, and inductive analysis was led by [deidentified initials first author] to group material with similar meanings into themes that were consistent with an Aboriginal and Torres Strait Islander perspective. These themes were further examined, led by [deidentified initials first author], to provide a nuanced cultural interpretation of participants' meanings and expanded by [deidentifed initials first author] from her experience. In the Discussion section, these interpretations are noted by using her name (deidentified initials first author).

Results

In-depth interviews or focus groups were conducted with 29 participants; eight Aboriginal or Torres Strait Islander cancer clients, four carers of these clients, and 17 cancer care professionals, including six IHLOs, at two large public hospitals in Queensland, Australia. The cancer care professionals included IHLOs, social workers, oncologists, radiologists, oncology nursing staff, and support service workers (accommodation and transport services) from both non-government organisations and state government departments. Thematic analysis of the data revealed four key themes regarding the non-financial costs of the cancer care experience: (1) anxiety about leaving home and missing family; (2) loss of control during cancer treatment; (3) health of the spirit; (4) social costs. What was considered important by researchers in this study was to promote the recognition of knowledge that Aboriginal and Torres Strait cancer clients have about their health from a cultural perspective. These themes have been identified as 'costs' for Aboriginal and Torres Strait Islander peoples as they are not only 'out of pocket' or non-financial costs but also spiritual, cultural, and emotional costs. These were deemed more significant than economic costs.

Anxiety about leaving home and missing family

Participants described how, for those who are away from their home community whilst accessing treatment, the impact is daunting and traumatic.

Yeah, and loneliness being here and away from family. That is a big impact – and sometimes it depends on how long they are here for treatment. They could be here 12 months like [name] *and they want to go home.* (IHLO)

Such experiences have substantial implications not only for clients' social and emotional wellbeing but also for their treatment. Being away from support of family and friends is difficult and often impinges on treatment. When asked about the importance of family support, an IHLO with an extensive experience in the field explained:

Definitely. [family support affects treatment] *It sure does, that is a big thing you know – If they don't have family support you know it impacts on their treatment whether they want to go through with it unless they have family or someone a supporting person you know they may not go ahead with treatment. They will not go ahead unless they have that family or cultural support.* (IHLO)

Some clients also experienced anxiety about coming to a large urban area to access care. Their fears, relayed to cancer care professionals, included worry about personal safety, worry about being taken advantage of by taxi drivers and anxiety about getting lost.

…you can definitely be taken advantage of, and that is what a lot of people are scared of from communities as well, they hear about [the city]. *They see things happening on the news and that as well can scare them away from coming down for treatment.* (Cancer Care Professional)

Some participants also expressed fear of hospital and the belief that the hospital is the place people go to die. This fear then gets confirmed if treatment/diagnosis is late and the cancer has progressed beyond treatment.

Something else that I've heard as well, people say, probably not on the financial but it's like they're scared to come down to the hospital as well because they think it's where people go to die. (Cancer Care Professional)

Agency and control during cancer treatment

There is little acknowledgement in the health system of the agency that Aboriginal and Torres Strait Islander people may bring to their own healing. Rather there is a series of complex chains of service delivery to negotiate and there is a presumption that health care providers' recommendations and priorities are paramount in the lives of those living with cancer. Participants highlighted, while health professionals might see it this way, the reality is that sometimes people cannot comply for good reasons.

The hospital make it a rule so when I go in for my operation I got to be there and then the person got to come there and pick me up and bring me home and then the person has to stay there the night to make sure that I am comfortable. Nine times out of ten there is no one here and then I got to ring up and so cancel it for another time because it is very hard to get transport and people to pick you up and take you there. (Client)

As described above, the hospital rules for quality care meant that it was difficult for the patient to decide themselves when they had treatment. Within the current models of service delivery in health and social wellbeing Aboriginal and Torres Strait Islander people have considerable experience at negotiation of complex issues. During this negotiation, some participants refused to be defined by the experience of living with cancer. While describing the difficulty of achieving a sense of control despite a cancer diagnosis several participants emphasised how they refused to be defined by the experience of living with cancer.

That's when my GP said to me "Well you want the good news or the bad news" but when she told me I had cancer I just laughed in her face for a reason. I didn't want to be sad. I didn't want to be put down, stressed out over cancer […] you got cancer the quicker it takes over your body. If you control your cancer in a way that I controlled it and I got on the best ways I can. (Client)

Another woman was unwilling to let her experience of cancer change her life as she had been very active in the past with her children and grandchildren.

Yeah and I still am [active]. It doesn't worry me since I had it out [cancer]- I don't think that there is any change- it hasn't stopped me from doing anything that I want to do. I think that I am just the same person. (Client)

The health of the spirit

Spiritual health is an essential to the health for many Aboriginal and Torres Strait Islander people. The two are interwoven — poor spiritual health can in turn affect physical health. Indigenous Health Liaison Officers were very aware of the need to facilitate client's trips to their home or family and spend a considerable amount of time enabling this.

There has been lots of time that people have passed [died] within their family and they have wanted to go back for funerals to say goodbye. We have tried our hardest to get them back for that and for some reason – unknown reason – the funeral is brought forward and you can't arrange it and also they have to pay their own way to go back to these funerals which they can't afford – you know when you are looking at $1,000 dollars whatever return. (IHLO)

Another example where IHLOs describe both medical and financial challenges in helping their clients get to funerals is described below.

So, we tried – they had the father's memorial and we tried to organise travel for [name] to go home. This was something like closure, but they [clinicians] refused. I think if the doctors would have allowed her to have more time at home, they might have approved it. But medically they couldn't. (IHLO)

One IHLO relayed the story of a client, a Sundowner (older person), who was passing away in hospital away from home and who attempted to have some connection.

And when people come from other areas and if they die here, they want to face [the direction of country] and that is one of their beliefs too. I had one patient in oncology, and he was dying, and he said

"can you face me that way" to the sun he wanted to just look out there and feel he was closer to being out west – he could see home somehow. (IHLO)

Social costs

A reduction in social connectivity as a result of accessing cancer care and cancer treatment was another cost identified in this study. Participants reported the impact on their usual social activities and not being able to afford to participate in the activities they once enjoyed.

Client: Yeah, it's been the change in lifestyle more than anything else.

Carer: Yeah, there's things we can't do now. I mean, we used to go out for dinner and things like that. But that, we don't do that now anymore. Can't afford it.

I used to do a lot with community involvement with lifesaving et cetera and I can't do any of that anymore. It's really impacting on how I used to live my life as well. (…) You can't do the stuff you used to enjoy doing. (Client)

Clients also felt the need to isolate themselves and limit contact with others, especially if they had a weakened immune system. This resulted in the experience of social isolation for some clients.

Like a family gathering or something like that, there was a lot of times we couldn't go…. But not just that. There was a lot of times where if somebody was there with a cold, I couldn't go because of the infection side of things in the immune system, or if I did go, I couldn't stay very long, and I'd have to sit there with a mask which made me feel like a leper anyway. (Client)

Discussion

This study provided greater understanding of the barriers to engagement — framed as a 'cost' of care — from the perspective of Aboriginal and Torres Strait Islander clients and carers and health professionals. The first important point is that personnel working within the health system are operating within, and influenced by, models of governance that perpetuate a deficit model of Aboriginal and Torres Strait Islander health.[22] While some individuals may work tirelessly to change this, and there are policy statements and initiatives to address it,[18] and some new public health initiatives aspire to focus on holistic approaches these often do not translate into benefits for practitioners and clients. There is an ingrained system where priorities for treatment align with the biomedical model and are posed as gaps between current Aboriginal and Torres Strait Islander health status and government set targets.[25] "We [Aboriginal and Torres Strait Islander people] know that medical treatments and interventions are vital for recovery, and we respond in our own way. We are more than just cancer clients and we have a lot of cultural and spiritual aspects to bring to our own healing. For example, many interviewees talked informally about visits from deceased, Murri [Aboriginal] doctors and how they use bush medicine" (deidentified: initials first author).

Second, this study provided greater understanding of the reasons, framed as a 'costs' of care, that Aboriginal and Torres Strait Islander clients and carers experience in accessing cancer services including treatment. By framing these issues as 'costs' a key contribution of the current paper is to draw attention to the way the health system itself is implicated in the disengagement of Aboriginal and Torres Strait Islander clients from treatment.

Findings from this study expand the common but narrow definition of cost as simply a financial burden, to explore other types of cost experienced by Aboriginal and Torres Strait Islander clients receiving cancer treatment.[21] A broader understanding of 'costs' is necessary to identify and overcome the reasons why Aboriginal and Torres Strait Islander clients experience higher rates of cancellations, non-attendance at clinical appointments and higher rates of hospital discharge against medical advice.[13,26]

Experience of treatment in the foreign environs of the hospital which — with the exception of the IHLOs — lacked basic cultural protocols was often traumatic. Ensuring a skilled workforce to provide culturally safe and competent care that is able to address the needs of Aboriginal and Torres Strait Islander people is an essential component if we are to improve their cancer outcomes. This includes increasing the access to Aboriginal and Torres Strait Islander Health Workers, hospital liaison officers and cancer coordinators (with both clinical and community knowledge) to actively assist patients, families, and carers to navigate the system and access services.

Inability to remain connected with family and community and fulfil social obligations such as 'sorry business', incurred both social and spiritual costs, leaving individuals feeling not just isolated but 'sick' in ways unrelated to their cancer diagnosis and treatment. Although not always framed in this way, our findings align with previous work that has identified 'barriers to accessing' cancer treatment which include the overwhelming administrative burden associated with client (and support person) transport and accommodation systems; the lack of cultural sensitivity in hospital environment or work culture; lack of access to interpreters or sufficient IHLOs to enable adequate support

for each client.[14,16,17,27–33] [Deidentified: initials first author] explains how people may have end-of-life, after-life, and other cultural responsibilities on country and may feel an obligation to undertake these. If they are unable, this may impact upon their wellbeing. "The presence of the patient at the funeral is part of their spiritual obligations to the deceased. Their presence affirms their relationships and their travel through this life and into the after-life. Sometimes people might prioritise these obligations over treatment". (deidentified initials first author)

Decision-making around the delivery of healthcare is often based upon cost-minimisation or cost-effectiveness, which favours the consideration of direct financial costs to the government funders of a health care system.[34,35] Such decision-making is justified based upon the premise of 'efficiency' and the notion that health outcomes are being maximised with a set budget, or that costs are minimised whilst producing the same health outcomes.[36] However, privileging financial costs over non-financial costs results in a bias in what and how services are delivered.

There are implications for health systems and practitioners arising from these findings. Most important, is the notion of relationally 'being held' during cancer treatment (deidentified initials first author). This is understood as the Aboriginal or Torres Strait Islander's spiritual, family and cultural learnings and responsibilities being recognised, valued, and supported. In other words, being held is a culturally secure environment. This requires the IHLO, client, and family and carers all to be central in the care process and interpret cultural and family responsibilities to the care team.[37] The wrap-around-care provided by IHLOs could then ensure that all systems, including

Figure 1: Being Held

Culture

Community practical support

Clinical care

Being held

Client
Carer
Family
IHLO
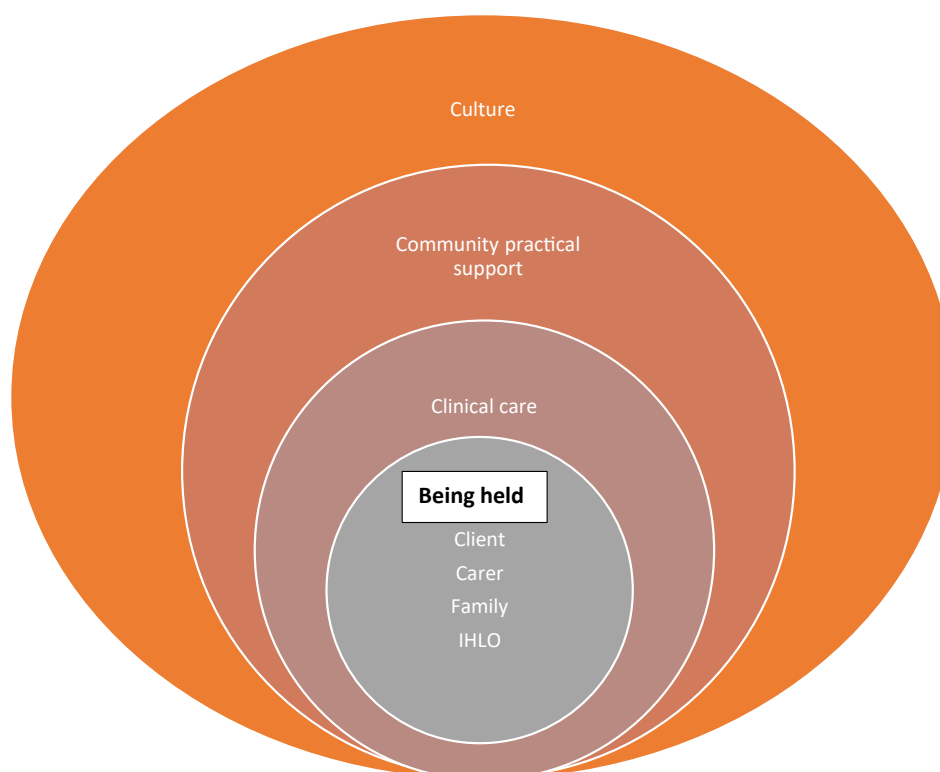
clinical care, financial support, and transport might acknowledge and integrate care for the spiritual, family, cultural, and practical needs. This relational, wrap around care by the IHLOs is critical.

[Deidentified initials of first author] mentions just one aspect that must be considered, "We might find that clients need time out from their medical treatment to undertake cultural responsibilities". The client 'being held' and the role of the IHLO in integrating clients' cultural, family, and spiritual responsibilities and needs into the cancer treatment models are demonstrated in Figure 1.

Strengths and Limitations

Strengths of this research included recruitment of participants from a large urban and a regional hospital. The regional hospital is the referral hospital for the entirety of North and Far North Queensland and the Torres Strait, which increased our representation of Indigenous people from regional, rural, and remote settings.[4] A particular value of this research is the opportunity to learn from Aboriginal and Torres Strait Islander researchers. Interviews were conducted and analysis led by an Aboriginal researcher in the regional setting, and a Torres Strait Islander researcher in the urban setting, each with deep community connections. This research was of importance to Indigenous Health Liaison officers who supported us with the data gathering. Evidence from our data collection was that the community felt that this research was valuable and that the community had a story to tell. Still, we note some important limitations to this work. This study was conducted prior to the COVID-19 pandemic. The findings are still valuable and relevant but should be interpreted keeping in mind that there have been some significant changes to the health system since data collection. Some of these changes, such as wait times, travel restrictions and visitor restrictions may have further impacted on Aboriginal or Torres Strait Islander cancer clients' non-financial costs.

Our intention was to provide information and opportunity to participate to all Aboriginal and Torres Strait Islander cancer clients. Staff turnover in the oncology unit in the regional hospital between study inception and data collection created challenges. Recruiting Aboriginal and Torres Strait Islander participants was difficult due to system issues with the recording of Indigenous status at the time of booking appointments. In the urban site, participants were recruited through researcher networks and collaboration with IHLOs who facilitated access to clients. These challenges reduced our ability to reach out to and hear the experiences and stories of a larger number of clients. Furthermore, Aboriginal and Torres Strait Islander peoples have had a history of being involuntary participants in research carried out over the last century, even into the late 1960s. Today there remains distrust and suspicion of studies and surveys for this reason and a number of potential participants voiced concerns to [deidentified initials of first author] of how their information will be used: "Sister I trust you but don't know what these white people gonna do."

Conclusion

We identify, in this paper, the non-financial costs of cancer treatment for Aboriginal and Torres Strait Islander clients and argue for a clinical cancer care model based in an Aboriginal relational concept of 'being held'. This would involve a conceptual shift from an Aboriginal and Torres Strait Islander client being an 'empty vessel' in need of clinical care to an individual who may have rich cultural and spiritual knowledge systems and family supports. This shift would require the client, family, carer, and IHLO to be the centre of the care system. Primarily it would be the IHLO interpreting the client's strengths and needs to the care team and this requires legitimising and resourcing this role.

Increasingly, interconnectivity, between the different domains in which treatment 'costs' are incurred, is occurring and health-systems personnel are working hard to accommodate the needs of Aboriginal and Torres Strait Islander clients and become patient-centred. There are, however, difficulties in some systems involving transport and meeting clients' needs for connection with family and community.

The concept of being held might more easily be enacted with more urgent work towards transforming treatment models — including through tele-oncology — that allow Aboriginal and Torres Strait Islander cancer clients to receive care closer to home where they are better able to share experiences, fulfil their social and cultural responsibilities, and make active decisions about how, where and when to engage with treatment.[38]

Ethical approvals

Ethical approval was received from the [Local ethical review details blinded for peer review] Human Research Ethics Committee (HREC) (number) and site-specific approval from [deidentified hospital and health service] and [deidentified hospital and health service].

Author contributions

RC – data collection, data analysis, drafting, and reviewing article. RP – data collection, data analysis, drafting and editing article. ST – conceptualization, data analysis, drafting and editing article. BA – data collection, review article. JT –data collection, data analysis, reviewing article. SL – conceptualization, data analysis, drafting, and editing article. EC – conceptualization, research design, editing article. LB – data analysis, drafting and editing article GG – conceptualization, research design, editing article. All authors have read and agreed to the published version of the manuscript.

Consent for publication

Ethical approval and consent forms for all participants included consent for publication.

Availability of data and materials

Acknowledgments

Author ORCIDs

Robyn Preston ⓘ https://orcid.org/0000-0003-4700-1521
Stephanie M. Topp ⓘ https://orcid.org/0000-0002-3448-7983
Judy Taylor ⓘ https://orcid.org/0000-0002-6761-095X
Sarah Larkins ⓘ https://orcid.org/0000-0002-7561-3202
Emily Callander ⓘ https://orcid.org/0000-0001-7233-6804
Lorraine Bell ⓘ https://orcid.org/0000-0002-0919-2577
Gail Garvey ⓘ https://orcid.org/0000-0001-5065-5716

Conflicts of interest

References

1. Australian Institute of Health and Welfare (AIHW), Cancer Australia. *Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview*. Canberra: (AUST): AIHW & Cancer Australia; 2013.
2. Australian Institute of Health and Welfare (AIHW), Cancer Australia. *Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview*. Canberra: (AUST): AIHW & Cancer Australia; 2021.
3. Gifford W, Thomas R, Barton G, Graham ID. Providing culturally safe cancer survivorship care with Indigenous communities: study protocol for an integrated knowledge translation study. *Pilot Feasibility Stud* 2019;**5**(33). https://doi.org/10.1186/s40814-019-0422-9.
4. Treloar C, Gray R, Brener L, Jackson C, Saunders V, Johnson P, et al. "I can't do this, it's too much": building social inclusion in cancer diagnosis and treatment experiences of Aboriginal people, their carers and health workers. *Int J Public Health* 2014;**59**(2):373–9. https://doi.org/10.1007/s00038-013-0466-1.
5. Commonwealth of Australia. *Closing the Gap on Indigenous Disadvantage: The Challenge for Australia Canberra*. Commonwealth of Australia; 2009 (AUST).
6. Brodie T, Pearson O, Cantley L, Cooper P, Westhead S, Brown A, et al. Strengthening approaches to respond to the social and emotional well-being needs of Aboriginal and Torres Strait Islander people: the cultural pathways program. *Prim Health Care Res Dev* 2021;**22**(e35–e35). https://doi.org/10.1017/S1463423621000402.
7. Pearson O, Schwartzkopff K, Dawson A, Hagger C, Karagi A, Davy C, et al. Aboriginal community controlled health organisations address health equity through action on the social determinants of health of Aboriginal and Torres Strait Islander peoples in Australia. *BMC Publ Health* 2020;**20**(1):1859. https://doi.org/10.1186/s12889-020-09943-4. 1859.
8. Walsh WF, Kangaharan N. Cardiac care for Indigenous Australians: practical considerations from a clinical perspective. *Med J Aust* 2017;**207**:40–5. https://doi.org/10.5694/mja17.00250.
9. Australian Institute of Health and Welfare (AIHW). *Indigenous Health and Well-being. Australia's Health 2018*. Canberra: (AUST): AIHW; 2018.

10. Shahid S, Finn L, Bessarab D, Thompson SC. Understanding, beliefs and per-spectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. *BMC Health Serv Res* 2009;**9**:132. https://doi.org/10.1186/1472-6963-9-132. 132.
11. Reilly R, Micklem J, Yerrell P, Banham P, Morey K, Stajic J, et al. Aboriginal ex-periences of cancer and care coordination: lessons from the cancer data and Aboriginal disparities (CanDAD) narratives. *Health Expect* 2018;**21**(5):927–36. https://doi.org/10.1111/hex.12687.
12. Shahid S, Finn L, Bessarab D, Thompson SC. 'Nowhere to room … nobody told them': logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment. *Aust Health Rev* 2011;**35**(2):235–41. https://doi.org/10.1071/ah09835.
13. Tranberg R, Alexander S, Hatcher D, Mackey S, Shahid S, Holden L, et al. Factors influencing cancer treatment decision-making by Indigenous peoples: a system-atic review. *Psycho Oncol* 2016;**25**(2):131–41. https://doi.org/10.1002/pon.3900.
14. Green M, Anderson K, Griffiths K, Garvey G, Cunningham J. Understanding Indigenous Australians' experiences of cancer care: stakeholders' views on what to measure and how to measure it. *BMC Health Serv Res* 2018;**18**(982). https://doi.org/10.1186/s12913-018-3780-8.
15. Jones B, Heslop D, Harrison R. Seldom heard voices: a meta-narrative systematic review of Aboriginal and Torres Strait Islander peoples healthcare experiences. *Int J Equity Health* 2020;**19**(222). https://doi.org/10.1186/s12939-020-01334-w.
16. Anderson K, Diaz A, Parikh DR, Garvey G. Accessibility of cancer treatment ser-vices for Indigenous Australians in the Northern Territory: perspectives of pa-tients and care providers. *BMC Health Serv Res* 2021;**21**(1):95. https://doi.org/10.1186/s12913-021-06066-3.
17. Garvey G, Cunningham J, Mayer C, Letendre A, Shaw J, Anderson K, et al. Psy-chosocial aspects of delivering cancer care to Indigenous people: an Overview. *JCO Glob Oncol* 2020;**6**:148–54. https://doi.org/10.1200/JGO.19.00130.
18. Topp S, Tully J, Cummins R, Graham V, Yashadhana A, Elliott L, et al. Rhetoric, reality and racism: the governance of Aboriginal and Torres Strait Islander health workers in a state government health service in Australia. *Int J Health Policy Manag 2022* 2022;**11**:1–13. https://doi.org/10.34172/ijhpm.2022.6750. 2022.
19. Mohamed J, Matthews V, Bainbridge R, Williams M. Who is speaking for us? Identifying Aboriginal and Torres Strait Islander scholarship in health research. *Med J Aust* 2021;**215**(8):383. https://doi.org/10.5694/mja2.51281. 383.e1.
20. Thurber KA, Thandrayen J, Banks E, Doery K, Sedgwick M, Lovett R. Strengths based approaches for quantitative data collection: a case study using the Australian Longitudinal Study of Indigenous Children. *SSM Population Health* 2020;**12**. https://doi.org/10.1016/j.ssmph.2020.100637.
21. Callander E, Bates N, Lindsay D, Larkins S, Topp SM, Cunningham J, et al. Long-term out of pocket expenditure of people with cancer: comparing health service cost and use for Indigenous and non-Indigenous people with cancer in Australia. *Int J Equity Health* 2019;**18**(1:32). https://doi.org/10.1186/s12939-019-0931-4.
22. Gee G, Dudgeon P, Schultz C, Hart A, Kelly K. Aboriginal and Torres Strait Islander social and emotional wellbeing. In: Dudgeon P, Milroy H, Walker R, editors, editors. *Working together: aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*. 2nd ed. Canberra (AUST): Australian Govern-ment Department of Prime Minister and Cabinet; 2014. p. 55–68.
23. Murrup-Stewart C, Whyman T, Jobson L, Adams K. Understanding culture: the voices of urban Aboriginal young people. *J Near E Stud* 2021;**24**(10):1308–25. https://doi.org/10.1080/13676261.2020.1828844.
24. Martin K, Mirraboopa M. Ways of knowing, being and doing: a theoretical framework and methods for Indigenous and Indigenist research. *J Aust Stud* 2003;**27**(76):203–14. https://doi.org/10.1080/14443050309387838.
25. Pholi K, Black D, Richards C. Is "Close the Gap" a useful approach to improving the health and wellbeing of Indigenous Australians. *Aust Rev Publ Aff* 2009;**9**(2):1–14. http://www.australianreview.net/journal/v9/n2/pholi_etal.html.
26. Valery PC, Coory M, Stirling J, Green AC. Cancer diagnosis, treatment, and sur-vival in Indigenous and non-Indigenous Australians: a matched cohort study. *Lancet* 2006;**367**(9525):1842–8. https://doi.org/10.1016/S0140-6736(06)68806-5.
27. Whop LJ, Valery PC, Beesley VL, Moore S, Lokuge K, Jacka C, et al. Navigating the cancer journey: a review of patient navigator programs for Indigenous cancer patients. *Asia Pac J Clin Oncol* 2012;**8**(4):e89–96. https://doi.org/10.1111/j.1743-7563.2012.01532.x.
28. Meiklejohn JA, Adams J, Valery PC, Walple ET, Martin JH, Williams HM, et al. Health professional's perspectives of the barriers and enablers to cancer care for Indigenous Australians. *Eur J Cancer Care* 2016;**25**(2):254–61. https://doi.org/10.1111/ecc.12467.
29. Garvey G, Beesley VL, Janda M, O'Rourke PK, He VYF, Hawkes AL, et al. Psy-chometric properties of an Australian supportive care needs assessment tool for Indigenous patients with cancer. *Cancer* 2015;**121**(17):3018–26. https://doi.org/10.1002/cncr.29433.
30. Meiklejohn JA, Garvey G, Bailie R, Walpole E, Williamson D, Martin J, et al. Follow-up cancer care: perspectives of Aboriginal and Torres Strait Islander cancer survivors. *Support Care Cancer* 2017;**25**:1597–605. https://doi.org/10.1007/s00520-016-3563-x.
31. Ristevski E, Thompson S, Kingaby S, Nightingale C, Iddawela M. Understanding Aboriginal peoples' cultural and family connections can help inform the development of culturally appropriate cancer survivorship models of care. *JCO Glob Oncol* 2020;**6**:124–32. https://doi.org/10.1200/jgo.19.00109.

32. de Witt A, Cunningham FC, Bailie R, Percival N, Adams J, Valery PC. "It's just presence," the contributions of Aboriginal and Torres Strait Islander health professionals in cancer care in Queensland. *Front Public Health* 2018;**6**:344. https://doi.org/10.3389/fpubh.2018.00344.

33. de Witt A, Matthews V, Bailie R, Garvey G, Valery PC, Adams J. Communication, collaboration and care coordination: the three-point guide to cancer care provision for Aboriginal and Torres Strait Islander Australians. *Int J Integr Care* 2020; **20**(2):10. https://doi.org/10.5334/ijic.5456.

34. Medical Services Advisory Committee. *Technical Guidelines for Preparing Assessment Reports for the Medical Services Advisory Committee*. Canberra: Department of Health; 2016.

35. Pharmaceutical Benefits Advisory Committee. *Guidelines for Preparing Submissions to the Pharmaceutical Benefits Advisory Committee*. Canberra: Department of Health; 2016.

36. Coelli TJ, Rao DSP, O'Donnell CJ, Battese GE. *An Introduction to Efficiency and Productivity Analysis*. United States of America: Springer US; 2005.

37. Brands J, Garvey G, Anderson K, Cunningham J, Chynoweth J, Wallington I, et al. Development of a national Aboriginal and Torres Strait Islander cancer framework: a shared process to guide effective policy and practice. *Int J Environ Res Publ Health* 2018;**15**(5):942. https://doi.org/10.3390/ijerph15050942.

38. Mooi JK, Whop LJ, Valery PC, Sabesan SS. Teleoncology for Indigenous patients: the responses of patients and health workers. *Aust J Rural Health* 2012;**20**(5): 265–9. https://doi.org/10.1111/j.1440-1584.2012.01302.x.

Appendix A Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.anzjph.2023.100085.