

To your door: Factors that influence Aboriginal and Torres Strait Islander peoples seeking care

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The Kanyini Qualitative Study

The Kanyini Vascular Collaboration (KVC) was established by Aboriginal and Torres Strait Islander as well as non-Indigenous health researchers, policy advisors, health economists, clinicians and health service partners with the aim of improving health outcomes for Aboriginal and Torres Strait Islander peoples (www.kvc.org.au). The Kanyini Qualitative Study (KQS) is the second project in a series of discrete yet inter-related studies conducted by KVC with Aboriginal and Torres Strait Islander communities and primary health care partners in New South Wales, Western Australia, South Australia, Queensland and the Northern Territory. In particular, the KQS was designed to explore principle barriers to and enablers of quality chronic disease care, in order to inform an understanding of what better systems of primary healthcare might look like for Aboriginal and Torres Strait Islander populations. This monograph, the first in the series, presents and discusses the findings of the KQS as they relate to the question of why Aboriginal and Torres Strait Islander peoples seek healthcare services for chronic disease.

Introduction

In comparison to non-Indigenous Australians, Aboriginal and Torres Strait Islander peoples experience significantly greater morbidity and mortality. On average, Aboriginal and Torres Strait Islander peoples are expected to live 12 years less than their non-Indigenous counterparts and they also suffer from higher rates of most chronic diseases [1]. Cardiovascular disease is the single leading cause of death among Aboriginal and Torres Strait Islander communities [2], diabetes remains at epidemic levels [3], and rates of chronic kidney disease are also disproportionately higher for Aboriginal and Torres Strait Islander Australians [4]. Together, these chronic conditions account for up to 50% of the life expectancy gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous peoples in Australia [5].

Given these poor health outcomes, it is of concern that access to and use of primary care services by Aboriginal and Torres Strait Islander peoples is often far lower than would be expected [6, 7]. In particular, Aboriginal and Torres Strait Islander peoples are almost five times more likely than non-Indigenous peoples to be hospitalised for conditions that are potentially avoidable by accessing appropriate primary healthcare. Despite the fact that 2.3% of the Australian population identify as Aboriginal and/or Torres Strait Islander [8], only 1.6% of Australian general practitioner consultations were with Aboriginal and/or Torres Strait Islander peoples [9].

Aboriginal and Torres Strait Islander peoples in remote communities are particularly disadvantaged due to the lack of available healthcare services [10, 11]. Where services do exist, it is often difficult to build lasting relationships with healthcare providers due to the high turnover of staff [12]. This, in part, may explain the lower use of services and higher rates of mortality among Aboriginal and Torres Strait Islander peoples in rural and remote communities in comparison to their non-Indigenous counterparts [13]. While a recent systematic literature review suggests that there are a number of models which may increase access to primary healthcare services in remote communities, these models have not yet been widely implemented or evaluated [14].

Aboriginal and Torres Strait Islander peoples living in urban centres can also be disadvantaged when it comes to accessing appropriate care. According to the 2008 National Aboriginal and Torres Strait Islander Social Survey, almost 30% of Aboriginal and Torres Strait Islander peoples over the age of 15 living in urban environments have experienced problems accessing healthcare services, and a further 10% were not able to see a general practitioner when needed [15]. While a number of studies have focused on chronic disease management in rural and remote settings, there is a substantial gap in the literature addressing chronic disease interventions for Aboriginal and Torres Strait Islander peoples residing in urban centres [16].

What is known suggests that Aboriginal and Torres Strait Islander peoples are generally less likely to use preventive healthcare services in comparison to their non-Indigenous counterparts [17]. Yet preventive healthcare, together with early intervention when symptoms do arise, is believed to be the most effective way of avoiding hospitalisation and reducing mortality rates [18].

A number of studies have investigated the reasons why Aboriginal and Torres Strait Islander peoples do not access or engage with healthcare services at the same rate as their non-Indigenous counterparts. Several broad issues have been identified, including the lack of culturally appropriate healthcare services, racist or discriminative behaviour by healthcare staff, the unaffordable cost of

seeking healthcare and a lack of time or ability to attend appointments [19, 20]. Some studies have also suggested various enablers to access; for example, ensuring that Aboriginal and Torres Strait Islander peoples were employed within the healthcare service would result in the development of strong relationships with patients and promote access [21].

This monograph contributes to this growing body of evidence by identifying the opportunities that encourage, as well as the barriers which discourage Aboriginal and Torres Strait Islander peoples from seeking healthcare. Perspectives are presented from Aboriginal and Torres Strait Islander participants, many of whom live with chronic disease, and from healthcare service staff who provide their care.

The KQS Monograph Series

This monograph focusing on *why Aboriginal and Torres Strait Islander peoples seek care* is one of a series which aims to explore the determinants, outcomes, and perceptions of chronic disease care as experienced by Aboriginal and Torres Strait Islander Australians. Subsequent monographs explore other aspects of care and well-being for Aboriginal and Torres Strait Islander peoples living with chronic disease, including:

- Monograph Two addresses why people remain engaged with or disengage from care;
- Monograph Three explores patients' and providers' understandings of healthcare and the caring relationship;
- Monograph Four investigates how healthcare systems influence the way in which people engage with or remain engaged with healthcare; and
- Monograph Five explores how wellness and well-being is framed, from the perspective of Aboriginal and Torres Strait Islander peoples living with chronic disease.

Method

Specifically, the KQS was designed to address the following research questions:

1. What frames Aboriginal and/or Torres Strait Islander Australians' engagement with care?
2. What does it mean to be looked after properly?
3. What are Aboriginal and/or Torres Strait Islander Australians' experiences of care for chronic disease?
4. What are the primary barriers to and enablers of care for Aboriginal and/or Torres Strait Islander Australians with chronic disease and their families?
5. How do we develop better systems of care for Aboriginal and/or Torres Strait Islander Australians?

The KQS was approved by four ethics committees, one in Central Australia, one in New South Wales and two in Queensland. Five healthcare service sites agreed to participate in the study. According to the Australian Standard Geographical Classification System [22], two services were in capital cities (RA1), two were in major regional centres (RA2-3), and one was in a remote area (RA4). Three of the

participating healthcare services were Aboriginal Community Controlled Healthcare Organisations (ACCHOs), and one was run by a government-administered Aboriginal healthcare service. The final site had services provided by a number of government healthcare services and four ACCHOs.

From July 2008 to February 2010, we conducted semi-structured interviews with 223 participants (Table 1), 126 of whom were Aboriginal and/or Torres Strait Islander peoples with and without chronic disease (Table 2), and 97 of whom were Aboriginal and Torres Strait Islander or non-Indigenous healthcare providers, healthcare service management or administrative staff (Table 3).

Table 1: Study Participants

	Aboriginal and Torres Strait Islander Participants (n=126)	Healthcare Provider Participants (n= 97)	Total Participants (n=223)
- Female	71 (56%)	62 (64%)	133 (60%)
- Male	55 (44%)	35 (36%)	90 (40%)
- Urban	43 (34%)	30 (31%)	73 (33 %)
- Regional	27 (21%)	38 (39%)	65 (29%)
- Remote/Very Remote	56 (45%)	29 (30%)	85 (38%)

Table 2: Summary of Aboriginal and Torres Strait Islander community participant characteristics

Participant Group 1: 'Community participants'*	No.	Regular Client	Irregular Client
Urb 1 (Queensland)	27	22 (17%)	5 (4%)
Urb 2 (New South Wales)**	16	11 (9%)	2 (1.5%)
Reg 1 (Queensland)	16	9 (7%)	7 (5.5%)
Reg 2 (New South Wales)	11	11 (9%)	0 (0%)
Rem 1 (Central Australia)	17	11 (9%)	6 (5%)
Rem 2 (CA)	6	4 (3%)	2 (1.5)
VRem 1 (CA)	14	14 (11%)	0
VRem 2 (CA)	16	16 (12%)	0
VRem 3 (CA)	3	3 (2%)	0
TOTAL	126	101 (80%)	22 (17.5%)*

*Abbreviations are explained in Table 4, below.

**The remaining 3 community participants included 1 family member, and service utilisation data were missing for 2 participants.

Table 3: Summary of healthcare provider participant characteristics

Participant Group 2: 'Healthcare providers'	No.	Aboriginal Identity		Type of Healthcare Service		
		ATSI*	Non-ATSI*	ACCHO**	Gov [^]	NGO ^{^^} / Private Sector
Healthcare providers						
Aboriginal Health Worker	17	17	-	16	1	-
Nurse	29	4	25	13	14	2
Doctor	10	-	10	8	1	1
Allied Health	6	1	5	5	1	-
Registered Nurse manager	4	1	3	2	2	-
General Practitioner manager	6	2	4	4	2	-
Aboriginal Healthcare Worker manager	3	3	-	1	2	-
Non-clinical manager	5	3	2	3	2	-
Board member	2	2	-	2	-	-
Chief Executive Officer	4	3	1	4	-	-
Administrative staff (receptionist; driver, etc.)	9	7	2	6	3	-
Key informant	2	-	2	-	-	2
TOTAL	97	43	54	64	28	5

* Aboriginal and Torres Strait Islander

** Aboriginal Community Controlled Organisations

[^] Government

^{^^} Non-Government Organisation

Data were analysed thematically and the themes which inform the reasons *why Aboriginal and Torres Strait Islander peoples engage with care* are presented and discussed below. In order to contextualise and signify key participant characteristics, codes (Table 4) are used at the end of each quote.

Table 4: Participant Coding

Ethnicity	Aboriginal and/or Torres Strait Islander = Aboriginal Non-Indigenous = Non-Indigenous
Role	Community participant = Community Administrative Staff = Administrative Health Practitioner = Practitioner Health Service Management (includes board members and chief executive officers) = Manager Key Informant = Key Informant
Gender	Female = F Male = M
Location	Urban site = Urb Regional site = Reg Remote site = Rem Very remote site = VRem

Results

A number of factors influenced “why and when” Aboriginal and Torres Strait Islander peoples sought healthcare. Both Aboriginal and Torres Strait Islander community (community) and healthcare provider (provider) participants explored the aspects of providing a healthcare service which would encourage Aboriginal and Torres Strait Islander peoples with chronic disease to seek out and engage with services.

The Concept of a Welcoming Space

Welcoming spaces where community members felt comfortable, accepted, and able to build strong and trusting relationships with a healthcare provider encouraged the community to engage with their healthcare service. References to the quality of medical services and the implementation of evidence-based practices were noticeably absent from any of the discussions relating to why and when Aboriginal and Torres Strait Islander peoples sought care.

A ‘welcoming space’ did not simply represent the physical place but also encompassed elements of the emotional (the sense of being supported and cared for), and relational (the quality of relationships between patients and providers). One important aspect of a welcoming space was the presence of Aboriginal and Torres Strait Islander staff. The capacity of the healthcare service to provide holistic healthcare was also often discussed. While community participants described a holistic service as one which embraced their perceptions of cultural appropriateness, practitioners tended to speak in more practical terms, including providing a ‘one stop shop’ which incorporated different types of medical care within the one facility.

Feeling Welcome and Accepted

Aboriginal and Torres Strait Islander participants described needing to feel like the healthcare service was “*their place*” [Non-Indigenous_Manager_F_Reg], a space free from judgement, where they were accepted and could be themselves. This feeling of cultural safety and security, and the importance of feeling welcomed and cared for was evident in the way participants spoke about their healthcare space.

I can only answer you for myself, but you could ask any other Aboriginal person that wants to be cared for and improve their health and to stay healthy, they'll tell you that the Doctors that work for the Aboriginal Medical Service, to my way of thinking and talking is they're good people. They really care for the Aboriginal people. And Doctor I'm not only saying that because I'm a regular and we know one another, I'm saying this from my heart and I know the people who attend this place and come here for their check-ups. They're very pleased with how they're treated. [Aboriginal_Community_M_Reg]

The use of health posters depicting Aboriginal and Torres Strait Islander peoples, as well as paintings and other artefacts that demonstrate a facility's commitment to providing culturally appropriate healthcare, was considered to be important.

...It's right from when you walk through the door, brother. It's when you walk in, you see the paintings up there, you see the artefacts, you know. All that sort of stuff makes you feel welcome and makes you want to sit in the waiting room for an hour to wait... half an hour, five minutes, whatever. Because you feel that, you know, you're okay there. Yeah. And the ladies in the front, they're lovely. They're all good. Really good crew. I don't think I've had a bad experience over there... [Aboriginal_Community_F_Urb]

Sometimes this resulted in a space that wasn't just a healthcare service. Instead, it was a place that Aboriginal and Torres Strait community participants wanted to come to for more than just their healthcare needs.

Everyone in my family uses [name of health service removed]...I like [the health centre] better...probably because I know everyone who works in there and they all know me. [Aboriginal_Community_M_Urb]

Relationships

For many community participants, the relationship between the patient and their healthcare provider was critical to determining whether they sought care. Strong relationships with healthcare staff were considered to be a fundamental factor in a community member's decision to engage with a healthcare service.

You fellas in there [staff in the health centre] give us, the community members, a reason to come in. I don't know whether you even know that. But because of the way you fellas handle all your responsibilities, you make us want to come there. There are lots of places in our state, in our nation, where it's because of the people within the organisation that people don't attend...You look at those organisations where people aren't going, why is that? [Aboriginal_Community_F_Urb]

Relationships with healthcare staff were considered by many participants to be just as - if not slightly more - important than the type of building, and/or the quality of medical care on offer. When strong and trusting relationships were formed, community participants reported feeling that they were welcomed, respected, accepted and cared for.

They're [Medical staff] caring, first of all. They care what's going on. Like everything. Like they'll ask, first of all health and they ask about home. And then with me, like I said, like time is the biggest thing that I don't have and they just take the time out just to say, something nice, like you know, like I'm anaemic so my doctor will look up [my blood results] and say, "Oh you're getting it up there, yeah very good woo hoo!" And I'll feel better just walking in, I didn't come in to see you about that, but that's good, like a help for me. [Aboriginal_Community_F_Urb]

It was not only about relationships with individual patients. Healthcare providers in particular appreciated that it was also "about community" [Non-Indigenous_Manager_F_Reg].

And having familiar faces in the community, like [name removed], is well-known in the community, [names removed], you guys are all out there and, you know, mixing with them and being part of the community, rather than just a service. So making them feel welcome here, and being part of the community, I think is a big issue. [Non-Indigenous_HP_F_Urb]

The Presence of Aboriginal and Torres Strait Islander Staff

Aboriginal and Torres Strait Islander staff - whether doctors, nurses, healthcare workers or administration officers- made a significant difference to the nature of the relationships that were created within a healthcare service. Community members talked about how Aboriginal and Torres Strait Islander staff helped to create the much - needed feelings of belonging and acceptance.

So, it's very important to have your own people and you feel open to talk to, that sort of stuff. You go to a non-Indigenous doctor and they look at you sometimes indifferent, and you can't be sort of more open to them, sort of thing. [Aboriginal_Community_M_Urb]

Community participants acknowledged that Aboriginal and Torres Strait Islander staff often supported this sense of belonging and being understood because of the shared cultural heritage and similar life experiences.

...oh the people, the facilities, and you just have that rapport with people there and they make you feel welcome so you tend to go back ... rather than just sitting in a mainstream hospital or a little surgery where you're the only little black face ... it's much better going to your own mob... [Aboriginal_Community_F_Urb]

Aboriginal and Torres Strait Islander practitioners were also seen as important conduits to the larger community and this relationship with the community was important for a number of reasons. Relative to non-Indigenous healthcare practitioners, Aboriginal and Torres Strait Islander staff were better able to establish relationships with the community and use these connections to disseminate information, as well as build the community's confidence and trust in the healthcare service.

They [members in the community] see me every day, I talk to them every day and we've got good relations between the community. Just tell them to look after their health and things like that, hey. And I tell them I got problems too, like you know, you got problems, I got problems- what I'm saying build their confidences up. [Aboriginal_Practitioner_M_Reg]

Aboriginal and Torres Strait Islander staff were also able to assist non-Indigenous healthcare workers to work more effectively with the community. In turn, this enabled the provision of better services to community members. For example, one healthcare service manager described how their Aboriginal and Torres Strait Islander staff were able to provide non-Indigenous healthcare practitioners with details about a patient which may otherwise have gone unnoticed.

The presence of Aboriginal health workers is crucial because they are members of the community...lots of the staff members live around the service and know people and see them socially and hear what people are saying and know the relationships and are able to say to the doctor "This is such and such a person, she's related to this person, this is the background of what's going on" and that's often really crucial. [Non-Indigenous_Manager_M_Urb]

In contrast, issues pertaining to confidentiality and visibility also discouraged some peoples from attending a healthcare service.

I love it. Except when you meet people you know in the corridors and that...so you'd go there and all the kids would come, and you'd see people and then the next day it's all, "Oh what you been going to [name of health service removed] for?" They wanna know everything. [Aboriginal_Community_F_Reg]

Providing Holistic Care

Community participants, in particular, valued healthcare services that were able to provide a more holistic sense of care.

They've got a high-quality preschool next door. They charge us bugger all compared to the rest of them. They pick them up and drop them off. They'll pick me up. They'll look after me. They look after my teeth. They look after me. If I need a lift, no worries. They'll come and pick me up. They'll actually be concerned. Like, I've got more people caring about me here than I've had in my own neighbourhood in the last five years, you know...And this year, I have been using them. And I've been a lot better off. [Aboriginal_Community_M_Urb]

While the benefits of holistic care were discussed by community members and healthcare practitioners, there were differing ideas about what holistic care meant. For community, a holistic service was often described as one that resulted in them feeling cared for in every sense of the word.

Yeah. It's the holistic approach over here. It's the whole bundle. You know, it's the environment, it's the people, it's the care, you know, the service, right through to, the whole lot. From admin right through to your doctors and where you're sitting. It's really good. [Aboriginal_Community_F_Urb]

Some healthcare providers are far more clinically focused and not always willing or able to see outside of the biomedical frame of reference.

People who come out of a biomedical world don't come often thinking they've got to learn first. They come thinking "That mob's got to learn and I've got to give them something and I am responsible for giving them something that will make their lives better"...And all this health promotion is based around giving [Aboriginal people] stuff that [they] don't know that [they] should know and a promise to make life better. [Non-Indigenous_Key Informant_M_Rem]

It may also be that the healthcare system actively restricts the implementation of a more holistic sense of healthcare.

[The clinic has] quite a coercive architecture to it. It's very restrictive and I've not worked in it much, but...it enforces passivity in that way; people can't in any way take any sort of intervention in their own health in that clinic. Even the nurses can try and subvert it but have trouble because of the way it's set up. So it's just a hard place to be a – it's not a community health centre anymore, it's like a clinical centre. [Non-Indigenous_Practitioner_M_VRem]

Understanding the importance of seeing beyond the patient's immediate illness appears to be something that comes about through practical, contextual experience.

But nobody told me that there was a difference but over the years I've learnt that. I guess when you're in my nursing training you're a hospitalbased nurse so you're looking at just the patient as it is, like you're fixed on just their illness but when I went to the community I had to look at a holistic approach. I was never taught that, it's what I've gained since 1981. Yeah it's quite amazing [Non-Indigenous_Practitioner_F_Rem]

While many Aboriginal healthcare services are already striving to provide a “holistic primary healthcare” [Aboriginal_Practitioner_M_Reg] service, additional opportunities to improve these welcoming spaces by sharing knowledge and resources between healthcare services also exist.

I guess, a more coordinated approach in clinical health workers instead of us having to struggle or compete with other health centres for that bucket of money to help train our staff, whereas if it's a collaborative approach, everybody's pulling together in the one direction, it, I guess, increases our bucket of funding, our resources, our materials, but it gives that holistic approach so as, what Government is now trying to, I guess, implement. [Aboriginal_Community_F_Rem]

Barriers to Seeking Care

Community members and healthcare providers described a number of practical issues which they believed might inhibit or prevent Aboriginal and Torres Strait Islander peoples from seeking care. In many cases these were related to the number of competing demands that Aboriginal and Torres Strait Islander peoples juggle on a daily basis. It appeared that there was never just one problem, but a range of issues which all needed to be solved before an Indigenous person could successfully seek care.

Because sometimes people miss out on their appointments because they don't have cars, they don't have money because they're all on welfare. And then there's a lot of children in the house, you've got to find a babysitter, you've got to take some kids with you, and there's a problem, and a lot of our people miss out on appointments that are very, very vital to their health issues, and they've got to go, and because of the area too...we definitely need transport for our customers. [Aboriginal_Community_F_Urb]

Some community participants spoke about the difficulties they or others faced in simply making a healthcare appointment.

...they've got different rules now. You've got to make the appointment to go to [the Aboriginal Medical Service] and if you haven't got an appointment then you've just got to wait...You miss out...well Aboriginal people they haven't got the phone, [or if] they've got phones...they probably have no credit or whatever and you know if you've got a mobile phone that's a real thing to ring up [the Aboriginal Medical Service] because they'll put you on hold, you've got to wait for this and then they wait and you hold on and then go to another section...Then you've got to pay for all the phone calls. [Aboriginal_Community_F_Rem]

Others spoke about finding it difficult to get to appointments, often placing their own welfare last while they juggled the competing demands.

I know my own self, I won't go unless I'm sickly, sickly. I've got to be sickly, sickly to go to see the doctor. Because nobody else will do my job if I take the day off. So, you know...I know there's a lot of us Murri ones that travel into the city. You know, and work in the city. There's a... lot of workers, it may even, you know, extend to young mums, maybe they themselves can't come for whatever reason during the day, you know, and they might have to wait for hubby to come home to look after the children so that they could go to the doctor..... [Aboriginal_Community_F_Urb]

Factors Associated with Seeking Care

Both community members and healthcare providers agreed that no matter how welcoming the space, many Aboriginal and Torres Strait Islander peoples only attended a healthcare service when they were experiencing symptoms of illness and, then, often not until these symptoms were particularly severe. In some cases, treatment was only sought once they were so ill that other people made the decision to seek treatment for them. Practitioners considered that it was possible that with so many members of the community diagnosed with a chronic disease, people had become desensitised to the symptoms or symptoms were considered to be normal and, therefore, care was not sought. A small number of healthcare providers had observed a tendency for patients to seek treatment earlier than had previously been observed. There was also a suggestion that some patients were acknowledging the messages provided within healthcare promotion programs, although not necessarily with a corresponding change in behaviour.

Mistrust and Unwelcoming Spaces

One of the primary reasons for delaying or not seeking care was a lack of trust of mainstream healthcare services. For some community participants, this mistrust was a result of firsthand encounters of racism and/or inferior treatment, while others were deterred by the stories they heard from others in the community.

...a lot of people didn't want to go there [the local mainstream health service] because they felt the place was unfriendly, the staff were not friendly towards them and there was a lot of attitudes happening, people felt they were discriminated against, and the place was very sterile ... it wasn't like a, it wasn't a comfortable environment ... and people spoke ... didn't speak in the way we speak ... like very abrupt, loud and abrupt, communication wasn't there too, you know? Just that lack of understanding in how you talk, the tone you use for Indigenous people ... so there was that, where there was no probably no cultural knowledge with the staff ... [...].Yeah, like discrimination, racism, or you know, just ignorance and no sensitivity and no understanding of Indigenous health issues... [Aboriginal_Community_F_Urb]

Healthcare providers also acknowledged that Aboriginal and Torres Strait Islander peoples were discouraged by experiences of racist and discriminatory behaviour and felt that these occurrences were hard to forget.

Now if you have got the adults who don't – who have never accessed healthcare services as kids because they were never available and their parents never accessed health services because one thing is that they were discriminated against, they were just not available. So they were kids then and so that's what, 40 years ago... that is why you see access, well at the hospital a lot more, they will be sick. [Non-Indigenous_Manager_M_Reg]

One healthcare provider even suggested that Aboriginal and Torres Strait Islander healthcare workers were treated poorly in comparison to their non-Indigenous colleagues.

Well if you have got a nurse who really treats that health worker disrespectful, like spraying them with fly spray before they walk into clinics. How could you expect the patient to go to the clinic with that? [Aboriginal_Practitioner_F_Rem]

Community members shared their personal experiences of being made to feel unwanted and uncared for when attending a healthcare service. In these instances, they were left feeling as if nobody had made an effort to understand their personal circumstances or needs, nor had they been treated with respect.

I went down [to a mainstream GP] a couple of weeks ago with my son, because I couldn't get up here [to the Aboriginal Medical Service]...They go, "Yeah, bring him down. It will be half an hour wait," like that...It was just the way they said it- the tone of their voices over the phone was rude and nasty. I didn't think I was getting cared for. But when I rang up [the Aboriginal Medical Service] and said "My son's really sick," they said "Just bring him up." [Aboriginal_Community_F_Urb]

Seeking Relief

Even when the healthcare space was welcoming and community members had built a strong and trusting relationship with healthcare practitioners, preventive programs were rarely accessed by Aboriginal and Torres Strait Islander peoples. Community participants supported this view, describing how they often waited until signs of illness were evident before they sought care.

What would make me choose [to seek care]?...I know I've got to go. Your body tells you, honest, it does. Inside you need, you got to go and get medical attention...There have been a few times like I've been drained and I would leave, let it go for a couple of weeks. Well like I said you get the signs. [Aboriginal_Community_F_Rem]

Community participants reported that some people did not seek treatment until the symptoms were quite serious.

Yeah, that was me exactly before, I was exactly like that. I'd walk every now and again, but it's not until something drastic or dramatic happens to you and then it makes you reassess your life and then you can see the path you were going down. Like when you are sitting in a bed and you have got three or four doctors doing different things... that's an eye opener, you know. I thought, "Oh, shit I was doing something wrong".
[Aboriginal_Community_M_Reg]

Many of the providers in this study acknowledged that Aboriginal and Torres Strait Islander peoples tended to use healthcare facilities as "a last resort." [Aboriginal_Practitioner_M_Reg]

... they wait until the very last minute until someone else will ring an ambulance or they just can't cope anymore and they will then access the health services and these are things that could have been treated earlier that could have not had such big complications. [Non-Indigenous_Manager_M_Reg]

What Sickness?

Some practitioners believed that feeling sick was such a common state of affairs for some Aboriginal and Torres Strait Islander peoples that they had become desensitised to their own suffering: being sick was considered to be normal.

I think a lot of them have got too used to feeling unwell over the years that they've accepted it...I don't know if that's true but to me I think, "God, I've seen your blood tests, I've seen this and seen that, you must be feeling shocking," but they may not say that and I think sometimes it's because they've become used to feeling that way. Because you think if they know how to feel well and what it feels like to be really well, then they'll want to get better. [Non-Indigenous_Practitioner_F_Reg]

With so many in the community living with chronic disease, some Aboriginal and Torres Strait Islander peoples spoke of not wanting to be confronted with a chronic disease diagnosis.

I don't know, I don't want to know what's wrong with me half the time, I'm getting around fine and that, you know ... you kind of get around fine and then go to the doctors and get a test done ... they find what's wrong with you ... and then you start stressing out about it ... that's the way I am, I think what you don't know, you know, whereas [my husband] he's different ... he's got to go and ... I even said to him if I get taken to hospital and they tell me I haven't got long to live ... don't tell me ... I don't want to know... I just really stress out...
[Aboriginal_Community_F_Urb]

A Shift towards Earlier and Preventive Treatment

A minority of healthcare practitioners described observing a small shift towards patients seeking treatment while symptoms were still relatively mild and, in some cases, engaging with preventive healthcare. Participants suggested a variety of motivators were associated with seeking early treatment and/or preventive care. These included the stark reality of everyday life in a community where many people were already ill, plus having a strong sense of personal responsibility for others.

I think that for the most part [the reason people present to the clinic] is people are feeling unwell and sick and that's when they actually come to the clinic but that's probably the predominant model. But there are also variations within that so some people, because of perhaps a lot of education over time, they will come for preventive health checks like women health checks...I think it's starting to change, very slowly, that people are coming to clinic. [Non-Indigenous_Practitioner_M_Rem]

Community participants suggested that family members often reinforced the messages associated with seeking preventive and/or early treatment. One community member spoke about how having someone in their family who had suffered from a chronic disease had triggered their more regular engagement with healthcare services.

I get checked every 12 months for diabetes. Because it's in my Mum's family. Because my Nan, she died when she was 65 of sugar. [Aboriginal_Community_F_Urb]

Another participant described how prompting from their mother, who had been diagnosed with diabetes, was crucial to their own decision to seek treatment.

Last time I [felt unwell], I had the flu...felt like I wasn't getting better... So I went to the Doctors and then they said that I might have a touch of diabetes...Only just, mum because she had, she's got that diabetes, she must have sensed that something was wrong with me because I wasn't healing you know when I should have...she's worried that way so that's why I went to the Doctors. [Aboriginal_Community_F_Rem]

Yet for others it was the fear of ending up like other people in their community which motivated them to look after their own health.

Well when you've got family history with sickness like that, you could end up getting it the same as them. So before you get it you have to try and stay healthy instead of worrying about it. [Aboriginal_Community_F_Rem]

Personal Choice and Autonomy

Personal choice, in relation to engaging with healthcare services, was discussed by a number of participants. Community participants pointed out that it was not the job of the healthcare service to ensure that people sought care but that it should be the individual's responsibility to look after themselves.

When I'm crook I just look after myself...Yeah. And I don't want anybody to look after me...No I never just tell anybody about my things...I keep it to myself. [Aboriginal_Community_M_Rem]

In some cases Aboriginal and Torres Strait Islander peoples may choose, at least in the first instance, to seek treatment through more traditional methods. Care from a healthcare service was not considered until they had explored other options.

Just staying [here in this Outstation], you know...Yeah, I live here. Just walk around and go hunting, you know?...I'll cut down bush medicine too like [bark from a] tree and boil it, and drink it...All the time...[it's good] for bad cold...Some tree for bad cold, and cleaning your kidney too...before I go the clinic, I try them...It works, it works real good like. Only, [for] real big sickness [do I go to the] clinic and everything. [Aboriginal_Community_M_VRem]

One healthcare practitioner spoke about the regular use of traditional methods to treat illness either in isolation, or in conjunction with biomedical healthcare.

I know some people approach Ngangkari [traditional Aboriginal healers] for some traditional healing and I think people tend to, like the Western Desert guys would tend to go to that as the first option and if it's not working quickly enough or in the way that they were hoping, then they'll come and access [medical] care. And at [community name withheld] probably it would be the opposite way around, people would come to clinic and get sorted and then would go to the Ngangkari directly afterwards also, for their input... But in both places it's a pretty regular part of the equation. [Non-Indigenous_Practitioner_M_Rem]

Discussion

When choosing to access healthcare, Aboriginal and Torres Strait Islander community participants look for more than just a medical facility. They want a physical, relational and emotionally supportive 'welcoming space' within which they can establish a strong and trusting relationship with healthcare service providers who care for more than just their physical needs. Healthcare spaces should evoke a sense of belonging, where patients and the broader community feel they are accepted and understood. For most people, the presence of Aboriginal and Torres Strait Islander staff members was integral to the creation of this 'welcoming space.'

Despite the presence of 'welcoming spaces,' treatment-seeking could still be delayed until symptoms were considered unmanageable, by either the sick person or their family. Accounts of clinics being unwelcoming spaces where racism existed discouraged people from seeking care. So, too, did the fear that a chronic disease diagnosis could irrevocably change their lives in a negative way. Practitioners sensed a degree of inertia around treatment-seeking possibly because chronic diseases were so common they were almost an accepted feature of life in many communities. While participants agreed that the individual's choice should always be respected and that it was their right not to seek care, experiences of racism and expectations about life being worse after a diagnosis discouraged Aboriginal and Torres Strait Islander peoples from seeking care.

Accessing Healthcare Services

According to Thiede et al [23], access to care consists of three equally important dimensions: First, knowledge of the available services and whether individuals are confident in availing themselves of the care they require within a reasonable timeframe is required. Second, the individual must be able to afford the healthcare, with direct and indirect healthcare costs being a barrier to use. Finally, the service must be perceived by individuals and their communities to be appropriate. The third dimension - acceptability - figured most prominently in this study. In particular, relationships, between providers and patients, as well as between providers and the wider community, played a

significant role in shaping the acceptability of healthcare services for Aboriginal and Torres Strait Islander peoples.

Candidacy, which recognises that “people’s eligibility for medical attention and intervention is jointly negotiated between individuals and healthcare services” [24, p. 6] provides a useful framework for exploring these social relationships. Specifically, participants spoke about two candidacy concepts - the *permeability* of healthcare services promoting the importance of feeling comfortable and welcomed, as well as the potential reasons for *resisting, or choosing not to engage* with care.

Developing a Permeable Healthcare Service

Participants were very clear about what constituted an acceptable healthcare service. It was about a place which featured distinctively Aboriginal and Torres Strait Islander symbols, including paintings, posters and brochures. It was also a place where people felt welcomed and accepted, where strong and trusting relationships could be built and where there was an Aboriginal and Torres Strait Islander staff presence. Space, in this sense, went beyond a physical place to include relational and emotional elements.

The need to move beyond the physical was also identified by Fredericks [25], who recognised the broader nature of Aboriginal and Torres Strait Islander healthcare. Fredericks believed that each aspect of a healthcare facility could unintentionally and sometimes intentionally convey something about the type of service being offered. For example, placing an Aboriginal and Torres Strait Islander healthcare service in the back of the building may suggest the notion of being relegated to an inferior position. Likewise, having a non-Indigenous receptionist could imply the need to seek permission, before accessing the service. Whether intentionally or unintentionally, spaces relay a particular understanding and belief about the world in which they exist and the relationships that exist within them.

Belonging, Acceptance and Understanding

Welcoming spaces were places where social relationships between patients and providers as well as between the community and the healthcare service, could be formed. From the perspective of Aboriginal and Torres Strait Islander participants, creating a space where community members felt they belonged contributed to their readiness to engage. Belonging is important because it prompts and promotes feelings of emotional support, security and acceptance [26]. Given past experiences of racist behaviour described by a number of participants, it is not surprising that Aboriginal and Torres Strait Islander peoples will seek out healthcare services where they feel they belong. Interestingly, a study by Harrington et al [27] found that the existence of a sense of belonging was also associated with a willingness to more actively engage with the healthcare service. Conversely, they also found that when Aboriginal and Torres Strait Islander peoples travelled away from the healthcare providers they knew, they were less willing to engage with care.

Aboriginal and Torres Strait Islander staff are key contributors to these feelings of belonging and acceptance [27]. Yet participants in this study also acknowledged that strong and trusting relationships with non-Indigenous healthcare providers could also elicit a similar sense of belonging and acceptance [26]. However, these relationships were more difficult to form, needing time to develop and a willingness on the part of the non-Indigenous healthcare provider to understand healthcare from the perspective of the Aboriginal and Torres Strait Islander patient and the broader community [28].

Understanding Perspectives

No matter how willing, practitioners often find it difficult to step outside of their own biomedical understanding of health [29]. Therefore, it was not surprising that in comparison to community viewpoints, which focused primarily on the caring relationships, practitioners also discussed medical perspectives.

This is not to suggest that healthcare practitioners generally are unaware of the need to be responsive to their patients' and/or the community's understanding of health. As indicated by the findings in this study, the healthcare encounter was seen by many practitioners as an opportunity to appreciate the meanings, beliefs, and assumptions about health and illness that each brings to a healthcare relationship. However, it was also recognised that a power imbalance exists between the providers of mainstream healthcare services and Aboriginal and Torres Strait Islander peoples. On occasion, practitioners in mainstream services have attempted to impose what they believe to be an objective biomedical perspective on the patient without attempting to seek out or acknowledge the patient's own understanding of their health and wellbeing [30].

One of the primary reasons given for preferencing the biomedical perspective is that it is believed to be based on evidence that is more objective, in comparison to, for example, Indigenous belief systems [31] which are often considered by non-Indigenous peoples to be less reliable because they are socially constructed [32]. However, Indigenous methodologists have rejected this view on the basis that research, including medical science, is modelled on and embedded within western epistemologies [33] which have been and continue to be "oblivious of Indigenous traditions and concerns" [34, p. 113]. Sociologists and social psychologists also acknowledge that biomedical beliefs are not objective but are instead influenced by prevailing views and a dominant western narrative, which continues to evolve within a socially constructed context [35]. Take, for example, the increased medicalisation of pregnancy and birth over the last century [36], as well as the growth in the number of diagnosable mental illnesses between the Diagnostic and Statistical Manual in the last five years [37].

A welcoming space is also, therefore, one in which the practitioner listens to and provides advice, taking into consideration the patient's own understanding of health. Healthcare providers who are not cognisant of the power they wield and are unwilling to consider their patients' beliefs and values will always struggle to comprehend why Aboriginal and Torres Strait Islander peoples choose to delay or refuse to engage with the care [38, 39]. Rather than focusing solely on the implementation of evidence - based treatment methods, our research shows that in addition to medical services, healthcare providers need to understand health from the perspective of the patient and their community.

Barriers to Care

A number of logistical issues, such as the cost of transport and distances to healthcare services also relate to the permeability or ease with which people living in remote areas can access healthcare [24]. However, rather than being the primary focus of concern for participants in our study, logistical issues were instead described as yet another hurdle that added to the difficulties that Indigenous people living in remote communities face in accessing care [40]. These obstacles could be overcome through the provision of outreach services to isolated communities [41] and the establishment of transport systems to ensure that Aboriginal and Torres Strait Islanders are able to reach clinics [42]. Barriers and solutions are usually context-specific and require a community-driven response to identify the particular issues which require attention in that community, before improvements to Aboriginal and Torres Strait Islander peoples' acceptance of and access to healthcare services will occur.

Creating a Community Healthcare Space

Creating a healthcare service which belongs to and is part of the community is critical to improving access to healthcare services for Aboriginal and Torres Strait Islander peoples. The concept that care is a community concern is a particularly important one, and is consistent with the definition articulated in the National Aboriginal Health Strategy [43], as well as, more recently, in the constitution of the National Aboriginal Community Controlled Health Organisation [44]. Health, from this perspective, is very much about the community's wellbeing which is considered to be as important, if not more so, than any one of its members [45]. From this perspective, healthcare centres need to embrace, connect with and become part of the community, ensuring direct community involvement in the development and management of services provided to the Aboriginal and Torres Strait Islander peoples they serve [21].

Community-controlled healthcare organisations provide the best opportunity for Aboriginal and Torres Strait Islander communities to contribute to the creation of these 'welcoming spaces' [46]. However, government-funded services can also replicate these 'welcoming spaces' within their own communities. Inala Indigenous Health Service is one example of a government-run healthcare service which has successfully implemented a number of key strategies aimed at encouraging Aboriginal and Torres Strait Islander peoples to access and contribute to their healthcare services [47]. Aboriginal healthcare workers, liaison officers, and receptionists have been employed, a culturally appropriate waiting room containing posters depicting Aboriginal and Torres Strait Islander peoples and their artefacts was created, and all staff have undertaken cultural awareness training. Importantly, information was sent out to the communities about the facility and community members continue to be actively encouraged to contribute to the development of their healthcare service.

Expectations about Healthcare Services

While welcoming spaces are important, they did not automatically result in people engaging with care. Individuals take stock of the potential options available to them, and make quite sophisticated decisions based, to some extent, on previous experiences, as well as on more broadly socially constructed expectations [48]. Thus, "[i]nteraction with others forms an essential element in the dynamics of decision making" [48p. 1101].

An extensive body of literature has already described how poorly Aboriginal and Torres Strait Islander peoples have been treated by healthcare services in the past [21, 32, 49]. The resulting legacy is that mainstream services are perceived as belonging to and for the primary benefit of Western populations [50]. Continued systemic racism further diminishes any trust that Aboriginal and Torres Strait Islander communities have in the ability of the healthcare system to treat them equitably [51]. Studies have also demonstrated how a combination of past and present discriminative practices coalesce to deter Aboriginal and Torres Strait Islander peoples from engaging with care [32, 52].

Even though many community participants had not personally experienced racist behaviour, the stories of racial abuse and discrimination experienced by others appeared to influence their expectations about the type of care they would likely receive in a mainstream clinic. As most people will be swayed to some extent, by the opinions of others [53], this response is not unusual. Given the fact that Aboriginal and Torres Strait Islander societies were constructed through language, the stories of others, particularly respected Elders, may still be a preferred method of disseminating information [54]. It may be the case that Aboriginal and Torres Strait Islander peoples place greater emphasis on the opinions of others, particularly those of their family, as well as other important members of their community [55], than non-Indigenous Australians.

Expectations about Life after a Chronic Disease Diagnosis

For Aboriginal and Torres Strait Islander peoples living in communities which are highly cohesive and connected, cultural obligations can sometimes outweigh an individual's needs [56]. As such, a chronic disease diagnosis may be seen as an impediment to the fulfilment of these obligations. Therefore, rather than acknowledging the possibility of a chronic disease diagnosis, people prefer to delay treatment, coping with the symptoms as best they can [57]. A further benefit may be the postponement of a potentially arduous medical regime [31].

Some Aboriginal and Torres Strait Islander peoples may deny any existence of their illness. Denial is a common and legitimate coping mechanism, often used by individuals who are confronted by the possibility of a serious and life-long illness. Aboriginal and Torres Strait Islander peoples may actively choose not to follow the routine prescribed by healthcare professionals, deciding instead to manage their symptoms in a way which fits within the context of their life [58].

Expectations of Normality

Practitioner participants also suggested that some Aboriginal and Torres Strait Islander peoples have come to expect or even accept chronic disease as a normal part of life because of its prevalence in their communities. While not specifically considered in light of chronic disease, studies [59-61] have found that a greater social acceptance of obesity reduced the impetus for overweight people to seek treatment. Similarly, Taylor et al [62] associated the continuous media coverage of alarming Aboriginal and Torres Strait Islander health statistics with a reluctance to seek a diagnosis and treatment for chronic disease. While the focus on disparities between Aboriginal and Torres Strait Islander and non-Indigenous healthcare outcomes can draw attention and resources for addressing these issues, it also means that the prevailing Aboriginal and Torres Strait Islander social identity is caught up within a narrative of disparity and illness [45]. Taylor et al [62] found that Aboriginal and Torres Strait peoples have "come to expect poor health" (p. 602) reducing, at least to some extent, the impetus for preventive or early treatment.

Changing Expectations

A very real opportunity exists to transform the way in which people think about chronic disease, as well as the treatment that they may subsequently require. Improving the cultural appropriateness of healthcare services by ensuring that racism and discrimination do not occur would significantly raise communities' expectations of the ability of healthcare services to deliver acceptable care. While a number of cultural training models have attempted this, few have succeeded [63]. One of the criticisms is that many cultural competency, cultural awareness and transcultural care frameworks, focus on teaching the healthcare provider about the patient's culture, ignoring altogether the cultural influences embedded within the provider's practice as well as the healthcare system more generally. A recent review of the literature, suggests the cultural safety framework may provide the best opportunity for improving the cultural appropriateness of healthcare in Australia [64].

Cultural safety [65] places the clear onus on the healthcare provider, rather than the patient, to ensure that the services are tailored to and culturally appropriate for every patient. Cultural safety aims to expose the ways in which power relations within the system shape healthcare interactions and encourages internal reflection, particularly with regard to the healthcare provider's own cultural lens [66]. One of the primary limitations to implementing cultural safety is that, to date, the model has not been well-defined and is, consequently, difficult to operationalise in a practice setting [67, 68].

It is essential to support people to live the life they want, despite chronic disease to ensure that a diagnosis does not result in people being marginalised or removed from their family or their broader community. Reframing chronic disease care with a focus on supporting the well-being of people living with a chronic disease would raise expectations about a brighter future. Understanding how Aboriginal and Torres Strait Islander peoples living with chronic disease can and do maintain their independence and sense of well-being is particularly important. In addition, ensuring that Aboriginal and Torres Strait Islander patients, their families, and the broader community are partners in care-planning has already been suggested as crucial to supporting well-being [21].

More generally, counteracting society's perception of an inevitable link between Aboriginal and Torres Strait Islander peoples and chronic disease will also assist in supporting people to expect, and perhaps even demand, better health for themselves and their families. Despite the existence of significant healthcare disparities, there are positive stories that tell of improved services to and healthcare outcomes for Aboriginal and Torres Strait Islander communities. For example, the clear evidence that primary healthcare delivered through Aboriginal Community Controlled Health Organisations is not only more acceptable to Aboriginal and Torres Strait Islander peoples [69] but up to 50% more effective than mainstream services, demonstrates the success of these organisations [70]. Similarly, a retrospective study of Aboriginal peoples living in Western Arnhem Land also demonstrated that regular outreach visits resulted in significantly better attendance and follow-up for specialist care [41]. Likewise, "swift and dramatic decreases in rates of renal failure and natural death" (page 475) were associated with a systematic program which treated renal and cardiovascular disease in the Tiwi Islands [71]. These examples demonstrate that improvements are possible and that early, and even preventive, treatment can result in improved healthcare outcomes.

A proactive approach is needed to change the negative expectations associated with seeking treatment for chronic disease. In addition to providing a welcoming space, moving health services

out of the facility and into the community may be one solution. Studies have suggested that for remote communities, outreach services where care is provided within the community setting improves not only rates of engagement with patients [72], but also demonstrates to communities that acceptable healthcare services are available [73, 74]. Outreach services not only provide a non-threatening opportunity to build relationships between healthcare services and the community [41], but, at the same time, allow the entire community to judge for themselves the acceptability and appropriateness of the service as well as individual healthcare providers[75].

A similar community outreach model of care may also be effective in urban centres. Community-based interventions are effective in reducing obesity [76], promoting oral health [77] and managing asthma [78], primarily because of the successful engagement with and involvement of marginalised urban communities. Such an approach may also further encourage Aboriginal and Torres Strait Islander urban communities to engage with and take an active role in developing a healthcare service which meets their particular needs. As has already been demonstrated by the ACCHO model, ensuring community members are partners not only leads to a more acceptable healthcare space [69], but could also demonstrate the preparedness of the healthcare service to provide appropriate and respectful care, as well as its commitment to the community.

Strengths of the Study

The QQS was designed to examine the factors influencing Aboriginal and Torres Strait Islander peoples' engagement with healthcare services, particularly in relation to chronic diseases such as diabetes, heart and kidney disease. Exploring the experiences of Aboriginal and Torres Strait Islander patients and their care providers through the conduct of rigorous qualitative research improved our understanding of the key drivers of health disparities.

A large number of Aboriginal and Torres Strait Islander community members and healthcare practitioners participated in this study. These participants came from a mixture of remote, regional and urban contexts. It is also important to note that the healthcare practitioners were drawn from the same health centres that provided services to the Aboriginal and Torres Strait Islander community members involved in this study.

The research team that undertook this study comprised a group of geographically dispersed Aboriginal and Torres Strait Islander and non-Indigenous researchers, many of whom are either medical or nursing staff. All of the team members brought a wide variety of perspectives and understandings to the research which further enriched the analysis and interpretation of the data collected [79, 80].

Limitations

Despite the large number of participants and the variety of contexts in which the study was conducted, it should not be assumed that the findings are necessarily transferrable to all primary healthcare services. The wide diversity of Aboriginal and Torres Strait Islander communities that exist in Australia today, each with their own specific health needs, requires a contextualised approach to improving healthcare services.

Conclusion

In this study we found numerous opportunities for improving Aboriginal and Torres Strait Islander healthcare services. Within the healthcare space, these focused on creating a 'welcoming healthcare space' where the entire community felt they belonged, were accepted and understood. We also found that there were a number of beliefs and expectations which discouraged or dissuaded people from approaching a healthcare service. In particular, experiences of racism, whether experienced directly or vicariously, through the experiences of others in the community, resulted in a reluctance to engage with care. There was also a sense that people were reluctant to place themselves in a position where a chronic disease diagnosis might threaten their way of life forever. Finally, findings from this study suggested the possibility that some Aboriginal and Torres Strait Islander peoples accepted the disparity narrative promulgated by the media. Changing these expectations will require time and effort. We suggest improving the cultural safety of health services, focusing on supporting people to live the life they want despite chronic disease, and counteracting society's expectation that most Aboriginal and Torres Strait Islander peoples have, or inevitably will have, chronic disease.

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