

Complex needs and limited resources: Influences on the provision of primary healthcare to Aboriginal and Torres Strait Islander peoples living with chronic disease

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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 fourth in a series being developed by the KVC, explores the issues which influence the ways in which primary healthcare services operate to provide care to Aboriginal and Torres Strait Islander peoples living with chronic disease.

Introduction

Australia's primary healthcare system has been described by the Australian government as one of the best performing systems in the world [1, 2]. Yet, some policy makers and practitioners see the system as complex and difficult to navigate [3, 4]. A contributing factor to this complexity is the lack of a consistent sector-wide approach to the provision of primary healthcare [5]. At one end of the continuum, comprehensive primary healthcare supports an holistic sense of wellbeing, which encompasses not only physical and psychological health but also attempts to address the underlying social and cultural determinants of wellbeing [6]. In contrast, selective primary healthcare is a more pragmatic medical model, less concerned with underlying social and cultural determinants or issues beyond illness and disease that may contribute to them [7]. While Australia espouses the benefits of and advocates for the implementation of a comprehensive model [8], in reality it tends to provide a more medically-focused primary healthcare service [9].

Funding models are believed to be another major contributor to this complexity. The majority of primary healthcare services are funded by the Australian Commonwealth government through the Medical Benefits Scheme [3]. The Commonwealth also provides a small amount of funding through grants, primarily for non-government, not-for-profit organisations. State and Territory governments also fund primary healthcare services [10]. The type of services and extent to which they are supported differs between states and territories [3]. One of the primary complaints levelled at state and Commonwealth funding models is that they are relatively inflexible, often impeding rather than supporting, for example, appropriately coordinated care between healthcare services [11].

Coordination between and collaboration amongst healthcare services affords a number of provider and patient benefits [12]. For example, substantial progress has been made in child survival by providing a coordinated continuum of care including skilled attendance at birth and strengthening early postnatal care [13]. Collaboration and coordination also help to ensure that scarce resources are shared across a number of services [14]. Yet, even when flexible funding models are available, collaboration with other healthcare services also requires staff who are aware of the existence of other services and have the time to coordinate a patient's care [11]. Staff shortages [15], together with a generally poor understanding among staff of other types of healthcare services available [16], can result in patients failing to obtain the treatment they require.

Over 90% of general practitioners, who are the first point of contact for many primary healthcare services in Australia [1, 17], work outside of the Australian public healthcare system [3]. In many instances, patients will require a referral from a general practitioner in order to access various services and receive a refund for all or part of the cost [11, 15]. Pharmacies are also privately owned and predominantly funded for the provision of subsidised medication through the Pharmaceutical Benefits Scheme. Other for-profit primary healthcare providers include psychologists and physiotherapists.

Providers operating for-profit practices, funded partially or entirely through out-of-pocket patient contributions, often find it difficult to operate competitively outside of an urban centre [18]. Therefore, rural and remote Australian communities are often unable to attract primary healthcare practitioners to their region. Instead, they rely on community healthcare centres, outreach services and even tele-health and tele-medicine to provide at least basic care. This can result in a lack of continuity of care or absence of continuous monitoring of patients, both of which are particularly

detrimental to people living with chronic disease [19].

Aboriginal and Torres Strait Islander peoples living in rural, remote and urban centres are able to access primary healthcare through Aboriginal Community Controlled Health Organisations (ACCHOs) and mainstream primary healthcare services [3, 20, 21]. In comparison to many mainstream services, which tend to provide a medically-focused service [6], ACCHOs aim to offer a more comprehensive primary healthcare model that attempts to address the underlying social and cultural determinants of wellbeing [22]. ACCHOs are, therefore, widely recognised as key to ensuring that Aboriginal and Torres Strait Islander peoples are able to access culturally-appropriate primary healthcare services that are responsive to the particular healthcare needs of their communities [23]. First established in the 1970s, there are presently over 150 ACCHOs operating across Australia [22]. The defining features of ACCHOs are that they are community-controlled and culturally-appropriate healthcare services, factors that have been particularly successful in supporting programs that aim to increase the acceptability of healthcare services to Aboriginal and Torres Strait Islander peoples at a local level [24].

Yet ACCHOs not only face similar complexities experienced by mainstream healthcare services, but also navigate a number of additional challenges. Despite some attempts by governments to improve the financial support available to ACCHOs [25-28], the level of funding provided to address the healthcare needs of Aboriginal and Torres Strait Islander peoples is insufficient [29, 30]. In order to sustain their services, ACCHOs are often required to seek funding from a number of different providers. This, in turn, makes the administrative and reporting requirements for ACCHOs arduous [31]. It also means that ACCHOs are required to balance the aims and objectives of multiple funders with their own [32]. In particular, the broader social and cultural programs that are at the heart of the ACCHO comprehensive primary healthcare service models, such as domestic violence and youth programs, are often at the mercy of one-off, short-term grants, making it difficult to sustain these types of services [31].

The authors seek to understand how the complexities experienced by patients and healthcare providers influence the ways in which ACCHOs, as well as government-funded healthcare services, are provided to Aboriginal and Torres Strait Islander peoples. A number of interview questions within the KQS encouraged practitioner and community participants to share their perceptions about the healthcare systems-level issues that impact upon Aboriginal and Torres Strait Islander peoples' experiences of care for chronic disease. In particular, healthcare provider participants (doctors, nurses, Aboriginal Health Workers, managers, administrative staff and board members) spoke about what impeded and/or facilitated their ability to provide care. This monograph focuses on an analysis and interpretation of the data emanating from these and other relevant system-level perspectives.

The KQS Monograph Series

This monograph is one of five which aims to explore the issues that influence the ways in which primary healthcare services provide care to Aboriginal and Torres Strait Islander peoples living with chronic disease. Other monographs in the series focus on:

- Why Aboriginal and Torres Strait Islander peoples seek care,

- Factors influencing whether Aboriginal and Torres Strait Islander peoples remain engaged with care for chronic disease over time,
- How Aboriginal and Torres Strait Islander peoples and their healthcare providers understand care and the caring relationship; and
- 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 separate 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 [33], 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 Health Organisations (ACCHOs), one was a government-administered Aboriginal health service, and the final site had services provided by 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 (Table 2) with and without chronic disease, and 97 of whom were either Aboriginal and Torres Strait Islander or non-Indigenous healthcare providers (Table 3), healthcare service management or administrative staff.

Table 1: Study Participants

	Aboriginal and Torres Strait Participants (n=126)	Islander Healthcare Participants (n= 97)	Total ProviderParticipants (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

These data were analysed thematically and the themes which inform *how and to what extent systems-level factors and issues impact upon chronic disease care provided for Aboriginal and Torres Strait Islander peoples* are presented and discussed below. This monograph explores the issues which are faced by healthcare services in providing care to Aboriginal and Torres Strait Islander peoples living with chronic disease. As healthcare services are socially constructed [34, 35], we were particularly interested in the relationship between healthcare providers and Aboriginal Torres Strait Islander individuals and communities.

In order to contextualise and signify key participant characteristics presented in the following results section, codes (Table 4) are presented 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 Healthcare Practitioner = Practitioner Healthcare Service Management (includes board members and chief executive officers) = Manager
Gender	Female = F Male = M
Location	Urban site = Urb Regional site = Reg Remote site = Rem Very remote site = VRem

Results

The findings within this monograph fall within three main themes: (1) under-resourced healthcare services as well as providers within these services were struggling to provide services for populations with complex needs; (2) at some level there was a cost to both patients and providers resulting from overburdened healthcare services; (3) yet despite these factors, many healthcare services were still able to respond to the needs of their communities. In particular, flexible delivery models and the presence of strong champions and leaders within healthcare services appeared to strengthen service delivery.

Complex Needs and Limited Resources

Some of the healthcare services were clearly struggling to meet the needs of the communities they served, with demand for services frequently out-stripping the ability of the organisation to respond. The increasing burden of chronic disease, as well as underlying historical, cultural and psychosocial determinants of health, result in complex healthcare needs in Aboriginal and Torres Strait Islander communities. Yet the resources required to respond effectively were not always available. The particular factors which appeared to contribute to overburdened healthcare services included the continuing struggle for funding, fragmentation of and even competition amongst multiple healthcare services, and difficulties recruiting and retaining staff, particularly in rural and remote areas.

Burden of Chronic Disease

The increasing burden of chronic disease was a common issue across all of our study healthcare sites. One remote practitioner, for example, described a significant increase in the number of people diagnosed with chronic disease over the last 10 years.

I started work here in '97, we had about three or four people on complex medication, you know, that we would be keeping up their dossette¹ to [them], checking them, trying to chase them around. Now we've probably got 40 people, 50 people on complex medication, and 250 on at least three tablets a day. So that's, I don't know, that's 10 times what it used to be. [Non-Indigenous_Practitioner_F_VRem]

The burden of chronic disease has led to healthcare services being inundated with patients, which has contributed to the sense that practitioners were tiring under the increasing severity and protracted nature of this situation.

Okay, I've been here for the last four years. It's actually a challenging place to be. But there [is] more pathology and there are more sick people here. And sometimes you get several things in one day and sometimes it's exhausting. Sometimes it's beyond what you have in your head. So that makes it really challenging. [Non-Indigenous_Practitioner_M_Reg]

The issue of insufficient time to deal with co-morbid conditions experienced by many patients caused considerable tension for practitioners.

You just don't have the time because they often come with [an illness] or they want a script...but it is never just a script and they have never had a blood test done for the last two years and they have got a fungal infection as well at the same time, they have got no money to buy the medication today and their blood pressure is through the roof, and you know, they have booked you in 20 minutes slots. [Non-Indigenous_Practitioner_M_Reg]

A perceived inability to be making in-roads into managing chronic disease for their patients led practitioners to feel the focus of care was often on “band-aid stuff” [Non-Indigenous_Manager_F_Reg], that they were “failing the community” [Non-Indigenous_Practitioner_F_Reg], and that they were caught in cycles of reactive care provision which compromised their capacity to undertake preventative approaches and deliver proper care in the face of increasing chronic disease and ill-health.

I guess most of the time the doctors are putting out fires. So they don't have a chance to really screen the risk factors if there's a whole waiting room full of fires. [Aboriginal_Practitioner_F_Reg]

¹ A system where endorsed health service staff dispense usually one week's supply of prescribed medications into a patient's purpose-built box which is labelled with specific times and days of the week.

Providers often spoke of rarely achieving the professional satisfaction of being able to demonstrate that they were making a difference to their patients' health outcomes.

When you're talking about preventative health you get a minority of victories that you have to take a public health perspective on...and that you're going to have to accept that the majority of the time, you know, eighty per cent of the time or maybe more, you're not going to get the change in behaviour that you want. [Non-Indigenous_Manager_M_Urb]

Operating within a Complex System

One of the primary concerns for healthcare service providers was the complexity of the healthcare system, with one practitioner suggesting that “*navigating the services that are available is a nightmare*” [Non-Indigenous_Practitioner_F_Rem]. Healthcare service staff were often required to take on an advocacy role, helping patients to navigate their way through the complex healthcare system.

And if they didn't have them [clinic staff] there as their, not even so much the case management, sometimes it's their advocate as well, within a system. So I think this clinic plays a great advocacy role of trying to get other places, institutions and services to actually understand the needs of this particular, and the dynamics of this particular patient family, whatever. [Non-Indigenous_Practitioner_F_Urb]

Navigating systems was particularly difficult for practitioners and patients in remote areas. One practitioner providing services within a remote location spoke about how the system was “*really cumbersome...you have to tell people that 'This is going to be a doctor journey.'*” [Non-Indigenous_Practitioner_F_Rem] referring to the need to manage the transfer of patients from one service to another. However, navigating the healthcare system was not necessarily any easier for people in urban settings.

I find that a lot of patients almost have to be their own case managers with chronic condition, and because they see so many specialists and sub-specialists, they're the only ones that are actually monitoring how will these things go together. And I find that what a lot of the patients do is use this clinic as their case management centre to coordinate the information, and sometimes to explain the information, re-explain the information, put it in a context of their life, and try and make those things work. [Non-Indigenous_Practitioner_F_Urb]

Inability to Address the Underlying Determinants of Health

A number of provider participants felt that many of the factors impacting upon the healthcare of Aboriginal and Torres Strait Islander peoples lay beyond their scope of influence. Some were pragmatic about this.

But it's not your job to turn [the “tsunami of disease”] around. That's a policy, a general social policy type issue that is going to make eighty percent of the difference and you might stick on ten or fifteen and I don't know, five percent from somewhere else. But you can't be expected to do it all though in health care you kind of forget that, I think some health workers might forget that. [Non-Indigenous_Manager_M_Urb]

Furthermore, some providers acknowledged the considerable impact of colonisation on the lives and health of Aboriginal and Torres Strait Islander peoples and how this reality required changes beyond the healthcare system.

And how do they expect [Aboriginal peoples] to change? You can't change someone like that overnight. You can't make them think that they'll all of a sudden wake up tomorrow and think, "Gee. I feel great today. I'm an Aboriginal"...I know that our role is not going to fix the whole thing because there's more involved than health, there's a bigger picture there. And there's a lot of work to be done... It's going to take a long time to change because too many people have been broken. [Aboriginal_Manager_F_Reg]

The complex social pressures and poverty experienced in some communities, which were well beyond the influence of healthcare practitioners, were also acknowledged by some practitioners.

You ask someone in [place name withheld] "Why don't you eat healthy? Why can't you just go into the store and get some fruit and veg and cook it up?" There's ten reasons why not. One, because they don't have enough money. Two, the store doesn't sell anything fresh. Three, they don't know how to cook it. Four, they don't have a fridge to store anything. Five, if they did cook up a beautiful big meal for their kids, every man and his dog'd be there to eat it...so there's so many more things on the Indigenous population's mind than health. [Non-Indigenous_Practitioner_F_Reg]

Other practitioners expressed concern over the hypocrisy of promoting lifestyle changes such as healthy food choices, when the reality was their patients were unable to act on these types of recommendations.

I was just going to talk more about the social determinants and the impact...you know the huge issues around chronic disease and the lack of supportive structure, whether that be infrastructure in places for people to go, even in congregating and doing education it could be in regards to the store - we start to do education about nutrition and it feels like a joke because of access to food, because of affordability of food and everything that goes with that about the type of store that is actually run, and how that's run. So sometimes I feel so hypocritical doing some sort of level of education and yet you know that there's no true [access]. [Non-Indigenous_Practitioner_F_Rem]

Other providers found themselves trying to fill gaps over and above what they believed their job to be. Boundaries around both the limitations of the practitioner role and patient expectations of care then became blurred.

We've just had an incident...here where one of my staff took on case coordination for some renal patients. And they loved the idea and responded very excitedly to this when they came to town ...but the lines weren't, I think the expectations on both sides were not clear. So two women from bush came in and started coming up here into this office...to ask this nurse to help them get housing in town...So he ended up becoming like in a social worker role. He wasn't clear where his role stopped and finished..... So that was really frustrating. [Non-Indigenous_Manager_F_Rem]

Struggling to Maintain Funding

While the demand for services to address complex needs remains high, the resources required to address these needs were often in limited supply. In particular, provider participants across the sites consistently described the funding environment within the Aboriginal community controlled sector as both challenging and uncertain. There was clearly a sense that monies may “dry up” [Aboriginal_Manager_M_Urb] and that funds from the government sector were finite. Although organisations anticipated additional funds from the federal government, one manager spoke of the frustrations associated with processing these requests, only to be disappointed with the outcome.

We were initially told by OATSIH [Office for Aboriginal and Torres Strait Islander Health²] that the Service Activity Report was the instrument they would use to identify funding gaps and unless needs were identified through that instrument, it would be difficult to gain the additional funds. That just hasn't happened. Previous feedback reports have identified [our] gaps in administration and health worker numbers but we have not received funds to meet that gap. That's what frustrates me. Those same frustrations exist when I think about the Closing the Gap money³. [Aboriginal_Manager_F_Reg]

However challenging, an uncertain funding environment did at times appear to encourage strategic responses within some organisations.

So that's why we have decided to start this [health service] men's group up so that we can be a separate body to attract funding, to get funding to the areas and we can start doing things like that, you know, and that will take the pressure off [the health service]. [Aboriginal_Manager_M_Urb]

Nonetheless, there were some healthcare services which were better-placed to manage funding issues.

Yes [securing non-OATSIH funding is] always an option. Thinking outside the box. That's probably an option for [our Aboriginal Community Controlled Health Organisation]. [We are] well-placed [financially] and asset-rich so we could apply for a bank loan and start to develop plans and building, etc. We are not due for any capital funding for a little while but, again, we need to think more like a business. We can do this ourselves and not rely on the government so much. Wouldn't that be nice? [Aboriginal_Manager_F_Reg]

² **Office for Aboriginal and Torres Strait Islander Health, which is** within the Australian Government's former Department of Health and Ageing, was established to give a greater focus to the health needs of Aboriginal and Torres Strait Islander peoples in mainstream health programs, and to assume responsibility for the administration of funding to Aboriginal and Torres Strait Islander community-controlled health. These responsibilities are currently shared between the Department of Health and the Department of the Prime Minister and Cabinet.

³ **Closing the Gap** is a campaign supported by the Council of Australian Government which aims to close the health and life expectancy gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians within a generation.

One practitioner described the situation as not so much about a deficiency of funds, but a lack of essential coordination of funding across multiple providers.

One of the meetings with people from [community 'A'] but they had a grant to do the research to have a look at what is needed for Indigenous people and it is all very fragmented. I said, "Here in [community 'B'] you have Uniting Care which are providing packages, and in [community 'C'], you have the Indigenous Compact and [community 'A'] is Indigenous Home Care. Where is the person here in [community 'B'] that can link all this?" [.....]The funding is there; it is getting someone to link it all. It is all very fragmented. [Non-Indigenous_Practitioner_F_Reg]

Some managers felt under pressure to compete with other services for funding. This was particularly true for a number of ACCHO staff who suggested that they were in competition with mainstream facilities for Aboriginal and Torres Strait Islander patients, as well as scarce resources.

But the fear is that unless you can really demonstrate that you're making a difference, they'll close you down because the mainstream practice down the road is now meeting the need... Unless you can really demonstrate that you're a vital cog in the system in your local area, the fear is that they will question if you're doing differently to the GP down the road and whether you should continue to receive funding. The GP has got [an Aboriginal] health worker, he's seeing Aboriginal people...When money is scarce, government tends to target Aboriginal affairs as the first place to cut back. [Aboriginal_Manager_F_Reg]

Limited Human Resources

Many of the healthcare services involved in this study were also struggling to maintain adequate staffing levels. One participant had worked with "at least 60 different RANs⁴." [Non-Indigenous_Practitioner_F_VRem] within the last five years. Rapid turnover of staff was a frequent problem in remote and regional areas.

So it's fairly high turnover for [an organisation of 130 employees]...In 2008-2009 we had 39 people leave. [Non-Indigenous_Practitioner_F_Reg]

In some cases this appeared to result in healthcare services 'making do' when recruiting staff, as opposed to identifying practitioners with appropriate skills and experiences.

All that management were interested in were 'bums on seats' to be able to say, "Oh well we've got a full staffing complement," but (a) I think that's very soul destroying to put staff in a position where what's being asked of them is beyond reasonable expectations and secondly if you know, these people are some of the sickest people in the country and they deserve really good practitioners who are really on top of it. [Non-Indigenous_Practitioner_F_VRem]

Both provider and community participants suggested that recruitment and retention of staff was difficult because staff members were not appropriately remunerated. Some believed that the Aboriginal community-controlled healthcare sector simply could not compete with mainstream healthcare services in terms of salaries.

⁴ Remote Area Nurses (RANs)

The issue is that [state government health department name withheld] pays much higher salaries than those offered through the [ACCHOs]. More recently [another ACCHO] has begun the rollout of health services in [name of region withheld] and the salaries they are offering, not just for health workers but also nurses, mean that we just can't compete. [Aboriginal_Manager_F_Reg]

In other cases, staff were less inclined to remain within the healthcare service for long periods of time. High staff turnover meant that it was often impossible to ensure continuity of care within many Aboriginal and Torres Strait Islander communities.

...and when I started three years ago in [community name withheld], there were I think 8-10 GPs [General Practitioners]...but we're running on 2 now...our continuity of care probably since we started has been absolutely abominable because there is no continuity. We've hardly had any doctor visits in the last year. [Non-Indigenous_Practitioner_M_Rem]

There was also a perception that the cycle of staff burnout could be contributing to the challenges of attracting healthcare professionals to fill positions, especially within remote areas.

So it's one thing to recruit people and have good strategies around recruitment and support, and then when we get people, the biggest loss is people who go away feeling completely burned out, or angry with the Department for the lack of support for them in their job, or lack of appreciation, or devaluing their contribution, and then they go away and they have a network of people that they talk to, which further discredits coming to work here for our department. [Non-Indigenous_Manager_F_Rem]

Often as a result, vacant positions went unfilled and staff who did remain were at risk of burnout attempting to make up for the shortage.

Because we don't even have some of the basic core services that we're meant to have, and if we do have them, we leave long gaps between recruiting and retention, re-recruiting into positions. And we don't have enough, really, on the ground, so, you know, if somebody needs physio, there have been periods where there's no physio available, and if there is a physio available, then there's no appointments available, because that one's already completely saturated...You can't just have unfilled positions all the time. [Non-Indigenous_Manager_F_Rem]

Even when new staff were found, those who stayed became fatigued as patients repeatedly sought them out in preference to having to go 'back to square one' with a practitioner new to their community.

Cos I've had people come to me quite proud [and say], "Oh [name withheld] when you were away they had that new nurse but I didn't go to her."...Like a loyalty thing...it's a good thing to say, but...the workload on the permanent staff becomes more hard because we do have that relationship. [Non-Indigenous_Practitioner_F_VRem]

The Consequences for Patients and Providers

Healthcare staff spoke about the significant consequences of an under-resourced healthcare service for patients. There were also a number of consequences for healthcare providers, not the least being the ethical dilemmas that arose in the face of providing care within a strained healthcare system.

Consequences for Patients

Health service staff reported that insufficient funding had serious consequences for their ability to provide effective and acceptable healthcare services, and this was likely to have an impact upon health outcomes for Aboriginal and Torres Strait Islander peoples. For example, the pressure to ration resources had resulted in ethical dilemmas whereby staff members were forced to prioritise where they should invest the most energy and other resources, frequently having to ask the question “*where’s my bang and my buck?*” [Non-Indigenous_Practitioner_M_VRem] in relation to competing demands for services.

In some circumstances, this meant that providers were required to decide between competing demands, even to the extent of preferencing one patient’s needs above another.

...so that young fella he was 24, he’s going to have his valve replacement. There’s not a lot wrong with him. If we keep up his Bicillins and things, he could live a long and happy life. So I think that is an ideal example of someone we do need to take that much care with. And then if I’ve got a 55 year old obese cardiovascular-diseased diabetic, how much energy do I put that way? [Non-Indigenous_Manager_F_VRem]

In other instances staff coped by focusing on the most basic needs of the patients.

You meet a lot of individuals out there who just see a very task-oriented approach, a very narrow spectrum of delivering care that’s not holistic, that’s more satisfying the system rather than the individual. So I don’t think we tailor things to individuals at all. I think we continually try to get people to respond to our systems. [Non-Indigenous_Manager_F_Rem]

One of the more concerning consequences of compromise was that practitioners in some sites reported avoiding preventative health checks and chronic disease screening, suggesting that “*it is a waste of time for us anyway to find these problems and then we don’t do anything*” [Non-Indigenous_Practitioner_M_Reg]. There was also the potential for the provision of general care to be impacted more broadly, with a practitioner in one remote healthcare service reporting that their ability to provide adequate attention to individual patients was hampered by shortages of time and resources.

So I always felt that to provide proper care was overly onerous, personal, like if I did 140 hour fortnights, I thought, “Oh that’s good.” And that’s not realistic...it’s not a healthy way to work, you know? ... I think some things were done properly...I think people got reasonable basic care, but not proper care. [Non-Indigenous_Practitioner_F_VRem]

One practitioner described the effects of insufficient staff being available to meet the community's needs.

There's an example today where we only had one doctor in the general clinic...and there may be between 60 to 70 people who have presented to the clinic today with an expectation of being seen and being treated and they will, if they wait, or they may be asked to go away and come back tomorrow or come back this afternoon. [Non-Indigenous_Practitioner_F_Reg]

In some cases, practitioners coped by minimising the type of care they provided.

She's [Aboriginal Health Worker] burnt out now and she turns up and she'll go and get people and she'll be helpful but she doesn't fulfil any of the clinical side of things anymore and I think that sort of stuff is really vital. [Non-Indigenous_Practitioner_R_VRem]

Consequences for providers

There were also consequences for healthcare practitioners who worked within these overburdened services, not the least of which was the risk of stress and burnout.

[T]hat whole stress, if people are stressed out, if the clinic staff are stressed out then of course there's less time to do, they can't get out of a clinic these days, there's no way you can be doing, for them, even if though they might have the greatest intentions, and I've heard them talk about this, "Oh we're going to do this education" – but it never happens, it will never happen...they can't get out of the clinic, they're stuck, inside. [Non-Indigenous_Practitioner_F_Rem]

Some practitioners in our study felt that they were operating in survival mode, over time coming to focus purely on the task in front of them rather than constantly trying to manage all patients' needs.

Let's see our diabetics every six months. You know? Let's make sure we do. Let's make sure we see our people in renal failure...yet every day comes and goes and there's numerous acute presentations and they're acute, sick people with an acute, simple thing like a cut on their foot. "Do I need a tetanus shot? But oh, look at that, I haven't had any of my anti-hypertensives for six months, I haven't had my blood sugar checked." "Oh, I've had my blood sugar checked quite frequently" – "Cos we do that really well, we do a lot of checking. But gee, look it was high, high 22, 18. Oh, "I had an HBA1C done a year ago – oh golly me, it was 14."...we let this ill health exacerbate. And so we try, but I think we're just hounded, you know? And it comes a time in the day when you go "Oh right, you just want your foot looked at, go for it." [Non-Indigenous_Manager_F_Reg]

There was also a sense from many practitioners of a personal cost that resulted from working with patients who were chronically ill.

...the best thing about [working in] renal is that you get to develop relationships with people but the worst thing is that you lose so many of them. We lost 17 patients in a year and if you think about how many people know that many people and lose them, and the impact that it would have on you over a long term, it could be very significant. So I'd like to see better support in the grief and loss, not just "Here's a card for EAS [Employment Assistance Service which provides free short-term counselling] go and see them if you need to." [Non-Indigenous_Practitioner_F_Rem]

Some practitioner participants clearly felt that the under-resourced healthcare system contributed to increased stress.

I just wonder now, like 20 years ago, the expectation was so different in what is expected of them now, probably the same staff ratios and yet they are so overburdened, so under-resourced, so stressed out, so burnt out. [Non-Indigenous_Practitioner_F_Rem]

For many Aboriginal practitioners there was the added responsibility of being both a healthcare practitioner as well as a member of the community.

I think, definitely, we need heaps more Aboriginal liaison officers and Aboriginal Health Workers than what we've got, and we need to find better ways to support them and address reasons why there's such a massive drop out, help them to be able to deal with the humbug and stuff that comes with the position. [Non-Indigenous_Practitioner_M_Rem]

Some practitioner participants acknowledged that healthcare staff were operating at unsustainable levels. This impacted on not only the individual practitioners but also on the level of care that they were able to provide.

They're [healthcare providers] pushed to the brink of that burnout, and stress is just always looming, sometimes it gets the better of them, sometimes what I'm seeing now, more of, is they're having shorter and shorter breaks, shorter periods of work so they're always having these holidays constantly, sometimes not knowing whether they're going to have staff to replace them and that's usually left until the last minute until that actually occurs, so all this sort of stuff you see and sometimes I think, my God, they'll be gone next week, you know, speaking to them on the phone and they're so stressed out and I'm actually surprised when I do the next visit to find them there. [Non-Indigenous_Practitioner_F_Rem]

Getting it Right Despite these Constraints

Despite struggling with the complexity of the healthcare system and the demands associated with increasing levels of chronic disease, several participants provided examples of how healthcare services were still able to respond effectively to the needs of patients. Four key elements were highlighted as central to achieving this: Having the right people on staff who are able to build strong relationships with diverse patients was considered essential. Participants also believed it was important that staff have strong connections, not only with other healthcare services but also with the communities they served. Promoting the flexibility of services to deliver quality healthcare in a demanding environment was also central to providing appropriate healthcare for Aboriginal and Torres Strait Islander peoples. Finally, participants believed in the crucial role of visionaries and

champions, as well as the need to further strengthen the capacity of Aboriginal and Torres Strait peoples to lead their own healthcare services.

It's About People

Aboriginal and Torres Strait Islander community and healthcare practitioner participants emphasised the need to have the right types of people in place in healthcare services to ensure that the quality of service is maintained. There are staff who “*can turn the patient’s whole experience into a negative experience no matter what.*” [Aboriginal_Manager_M_Reg]

And that’s that whole thing, you need people who actually understand. It’s not just the health worker, or the doctor, or the nurse who’s important. It’s the driver, it’s the person who organises the appointments, and it’s the person who takes the address of people and keeps that up to date. If those jobs aren’t done properly, you can’t do systematic chronic disease [care]. [Aboriginal_Manager_M_Reg]

Clinical staff who were able to build strong relationships with patients were also thought to be important assets for a healthcare service.

I think [community name withheld] has a smaller community where everybody knows each other, and the health workers do know everybody there. And I think the health workers are able to connect with their clients better. [Non-Indigenous_Practitioner_M_Reg]

The people singled out for special mention were Aboriginal and Torres Strait Islander healthcare staff working in a variety of ACCHO and government-funded Aboriginal healthcare services.

Yeah, yeah, he’s [Aboriginal Manager] completely invaluable, obviously, in attracting recognition and support and real-type support in the way of money to actually make things happen, but also just from a professional point of view, that’s half of it. The other half is actually been making the actual care happen, and that part of it isn’t just around [their] ability to talk to people. That’s around having things in place around clinical care and the actual processes and utilising the things that are there fully for their intended purpose...I mean he has a great ability to maximise the potential and the policies and the incentives that are there, to get the most out of them to make things grow. [Non-Indigenous_Manager_M_Urb]

While Aboriginal and Torres Strait Islander staff may not stay at one service forever, strengthening the capacity of staff was of benefit for Aboriginal and Torres Strait Islander healthcare overall.

We should be in a position where if staff get trained while they’re here and then they leave that’s their choice. For me it’s about “Yes we have another Indigenous person trained up, excellent, isn’t this a good thing?” [Aboriginal_Manager_F_Reg]

Relationships were believed to be particularly important when providing care to people with chronic, as opposed to acute, conditions. Preparing healthcare professionals for this work may be particularly important.

We run preventable chronic disease workshops every year for new [registered nurses], but I also talk to the hospital staff, and we talk about the differences of receiving acute care

versus chronic care, where you've got no cures, the patient's going to have long-term contact with health services as opposed to short curative-type interactions, where relationships are very important because this is, often, chronic disease is associated with a loss of sense of self, can be associated with depression and all those things. [Non-Indigenous_Manager_F_Rem]

The Role of Visionaries, Leaders, Managers and Champions

Having key staff in management positions who have the capacity to envisage the way forward and drive an organisation towards the identified path was discussed at length by a number of provider-participants in management positions.

[The CEO] is a visionary. [If not] for his vision of where he thinks we should be, pushing it, I honestly believe that we'd still be back... We look at where we were seven years ago, and as I said we were almost closing the doors then. [Aboriginal_Manager_F_Urb]

When attempting to reform systems of care, provider-participants believed that strong clinical leadership was important.

Strong clinical leadership, I think, is one of the most essential things. In the end, you have to sell it to clinical staff, and if they don't approach things in a systematic way, and if they don't see the quality-improvement process as important, you're lost right from the start. This is the issue in places like [name of region withheld] and other areas where it's really hard to drive change because you have to have somebody credible, really putting in a lot of time and energy in driving change. And that comes back to a lot of the relationship stuff, as well as systematising the teams, and just ensuring everybody knows where they fit into the picture. [Aboriginal_Manager_M_Reg]

Leaders could be found at all levels of an organisation and were seen as integral for inspiring trust and engagement, as well as maintaining a healthcare service's links with the community it served.

They're very strong leaders in themselves, and people know them. People know them...like I said you've got no hassles with ringing [nurse unit manager's name withheld] and saying "I need to do this. This is what I need," and she accommodates you, or if she can't, she'll find someone that can. [Aboriginal_Community_F_Urb]

The one drawback was the uncertainty that comes from over-reliance on one or two key individuals with no clear succession plan in place, should they leave.

So I think the fact that we all get on well and there's Indigenous leaders there who give us all legitimacy makes the place work. But, we need to be careful because, as you say, [names withheld] aren't spring chickens and that's something that worries me because once they go, like, then you lose that legitimacy and you just wonder what the community will think of the place. [Non-Indigenous_Manager_M_Urb]

The importance of ensuring a succession plan for future leaders was therefore raised as a key priority.

And I guess that's one of the really heartening things about this organisation is the fact that there are a lot of younger people than me--than us grey-haired old things-who just have so much talent and so much leadership ability and I feel good for the organisation in the long term. If people can stick around and we can nurture those staff, they're the next lot of leaders. [Aboriginal_Manager_F_Reg]

Healthcare Service Connectedness

Connectedness to communities, as well as to other primary, secondary and tertiary healthcare providers, was another common theme. The ability to forge good relationships was believed to improve the provision of systematic chronic disease care and enhance individual patient care.

Establishing links between a healthcare service and the community it served was discussed at length by both community and provider-participants, at one site in particular. One participant described how other healthcare services “just open and then they close,” [Aboriginal_Community_F_Urb] which contrasted with their facility.

...the service itself has done a lot of good work with agencies and the community and has a really high profile in the community ... it's got a community arm to it. [Aboriginal_Community_F_Urb]

Community events that providers attended, especially outside of work hours, built trust with the community and improved the uptake of healthcare services within communities.

...so they came outside their [work] time ... you know, they gave up their time to come out there ... [time] with their family to come and, you know, do the health check with us ... and, you know, it's about ... that's about getting out there and being heard ... and because they'd been out there doing that ... people are accessing [the health service] because of the worker... [Aboriginal_Community_M_Urb]

Participants noted that engaging with the community was crucial to helping to provide solutions, including setting priorities for the service.

So we're getting a chronic disease [program] down at [place name withheld], starting next month...it's a whole new role for this person and the manager said, “Okay, go out into the community, see what feelings are, you know, do a bit of an audit, what are the priorities,” and then we start looking at tackling some of those issues. So, you know, we go from there. [Aboriginal_Manager_M_Urb]

Conversely, participants believed a lack of collaboration with communities made the provision of care particularly difficult.

I am really, really, really, really angry with [healthcare service] about is the absolute total lack of engagement with the community as far as trying to have any dialogue between health staff and community members. And I realise that you probably start off poles apart but if you're not even having a dialogue, how can you ever find out where your common ground is? How do you form a partnership if you don't actually even have any way of communicating with people? I mean other than the one-to-one, you know, like, obviously, that happens all the time. But as far as a community and health service goes, there's just nothing. [Non-Indigenous_Practitioner_F_VRem]

While collaboration with communities was emphasised by participants, networking with other service providers was also believed to be beneficial, particularly insofar as they sought to broaden the range of services that patients could access.

...you don't necessarily have all these multi-disciplinary team people who are working for you...So they will all come and give presentations, even though they don't work for us, we sort of have an understanding or an agreement where they come here and make that program work. If we had to do that by ourselves, we don't have that capacity within the organisation, but we do have the capacity to bring all those people and coordinate that, for them to be in the room at the same time as those people who will benefit from their services. [Aboriginal_Practitioner_M_Reg]

A senior manager within an ACCHO spoke of the additional benefits that came with collaboration.

The positive [of the partnerships] is I think that you can get pretty much a good picture of what's happening across the region and across the state, of what's happening in health and being able to just keep on top, instead of doing that isolated "Oh we're just here at [health service name withheld] and we'll just do our thing." It's actually keeping abreast of all the new things that are happening across the state, new initiatives that are coming out. That's the really good part of it and plus the fact that it's like a joint or collective approach towards health for our mob so that's a good part of it. [Aboriginal_Manager_F_Reg]

Flexible Delivery Systems

Flexible delivery systems were considered by many participants to be integral to effective chronic disease care. Many participants spoke about the tension between appointment and walk-in systems. Staff at one healthcare service talked about their unsuccessful attempt to implement an appointment system.

Unfortunately, we did that and the only thing that was missing was the patients. We were the happiest, most professional staff, and the patient numbers actually dropped right off. [Aboriginal_Manager_M_Reg]

A number of provider-participants described other attempts which systematically addressed patient flow through healthcare centres whilst also remaining responsive to the needs of their communities. At one site, this involved implementing practical measures, such as employing "a specific 'walk-in doctor' to see walk-ins" [Aboriginal_Manager_M_Urb]. Elsewhere, staff advocated for a hybrid model, with mixed results.

We have tried appointments. We found that not everyone turned up for appointments. We have tried a mix, that is, some doctors with appointments, some with walk-ins. That doesn't necessarily work. You always need to be prepared for the unexpected. If [our people] are sick...they expect that they should be able to present to clinic and be seen. [Aboriginal_Manager_F_Reg]

At the above site, there was a particular emphasis on embracing a 'culture of flexibility' within the organisation. This involved fostering a mindset in management within the healthcare service that valued the capacity to "plan for chaos." [Aboriginal_Manager_M_Reg]

So it's how you do that properly and get the balance right...you can make the best out of people being people and turning up whenever they feel like it and 10 minutes late for a 10 minute appointment. Which puts your whole day out. But that's the way it is. And if you don't plan for that, then it's not going to work. [Aboriginal_Manager_M_Reg]

Participants also demonstrated flexibility in the ways they discussed changes to the delivery of healthcare services on the ground. For example, some practitioners spoke about moving away from a heavy reliance on patients coming to healthcare services, embracing instead the need to get care 'out of the clinic' and "Getting where people are." [Non-Indigenous_Practitioner_F_Urb]

Discussion

This monograph explores the issues encountered by healthcare service staff in providing care to Aboriginal and Torres Strait Islander peoples living with chronic disease. Encouragingly, our findings suggest that the vast majority of healthcare providers interviewed felt they were already working hard to provide appropriate healthcare for Aboriginal and Torres Strait Islander peoples living with chronic disease. Participants in our study did, however, acknowledge that healthcare providers faced a number of obstacles which ultimately impacted upon their ability to provide the quality and type of care they would like. Many had experienced physical, vocational and emotional fatigue as a result of having to deal not only with high levels of chronic disease within the communities, but also with a complex healthcare system. This was exacerbated by the fact that many of the healthcare services were also under extreme pressure, and were not always able to meet the needs of the community they served. Funding constraints, high employee turnover, and shortages of other resources reduced the ability of services to support not only their patients, but also their staff.

Organisational Constraints

A key finding of our study involves a sense that many of the participating healthcare services were overburdened and under-resourced, elements that, in turn, meant that their ability to function effectively was constrained. Other studies have identified a range of factors that inhibit the ability of healthcare services and their associated systems to provide the quality of healthcare to which they aspire. Alford [36], for example, noted a number of concerns pertaining to the level of funding which resonate with the findings of our study. One of these – a reliance on short-term funding [37] – is, perhaps, born of the assumption that ACCHOs only supplement mainstream services and, therefore, don't require the same level of financial support as other mainstream healthcare services. In addition to short-term funding, participants in our study also discussed the complexity of funding applications and reporting requirements. In order to make ends meet, ACCHOs often need to simultaneously manage funds from multiple state/territory and federal agencies, as well as non-government organisations [10]. Healthcare services that are able to employ senior staff with the skills required to identify, obtain and manage funding are thought to be relatively well-off, while smaller centres, particularly those in rural and remote areas that cannot afford the same level of expertise, may be at a distinct disadvantage [38].

At the same time, healthcare services in our study were struggling to recruit and retain appropriately skilled and experienced staff. While the majority of participants focused on the employment of clinicians, including doctors, nurses and Aboriginal health workers, a small number also recognised the need to attract and retain organisational leaders who could effectively and efficiently manage

the service. A number of specific issues influence the ability of ACCHOs, in particular, to build a team of qualified and skilled clinical and managerial staff. Primarily, these relate to the ability to compete with the wages and conditions offered by mainstream healthcare services, including the level of salary, length of contract and opportunities for professional development [37]. The ongoing shortage of skilled people within the healthcare sector more generally [39] further exacerbates difficulties with the recruitment and retention of staff to ACCHOs. While also evident in urban settings, these problems appear to be of particular concern in regional and remote areas [40].

Complex Patient Needs and Insufficient Resources

With the increasing prevalence of chronic disease [41], primary healthcare services have had to shift from an almost exclusive focus on acute conditions to one that also considers the management of chronic disease. Rather than one-off treatments, chronic disease often involves the management of complex conditions that occur over a longer period of time, thereby necessitating a longer relationship with patients. Ensuring that primary health care services are ready and able to respond to this change can be a major challenge for both primary healthcare managers and practitioners. While primary healthcare services are best placed to provide effective chronic disease care [42], managing this shift in focus only adds to the degree of complexity within an already complex environment [43].

While a number of tactics, strategies and supports ensured that staff were able to operate within this difficult environment, functioning with limited resources left some healthcare providers feeling as though they had little choice but to compromise on the effectiveness and appropriateness of the care they provided. Similarly, Enns and Gregory [44] found that increased workloads and complexity of tasks required nurses to compromise on their vocational values and the quality of treatment they provided to patients. As a consequence, these nurses reported feeling “frustrated, exhausted and alone” [44p. 342], particularly when it came to deciding how care could, as opposed to should, be provided. Nurses were more likely to leave the profession when they were forced to compromise on the quality of care they provided to patients [45].

Compromise also occurred at the healthcare service level. Participants in this study spoke of recruiting practices that were sometimes based on ‘making do,’ rather than identifying staff with appropriate skills and experience. In an environment characterised by staff shortages and exacerbated by the reluctance of some practitioners to work in rural and remote locations, there may be a tendency to overlook, ignore or even discount the importance of employing staff who are both qualified and able to provide the type of care needed [46].

In addition to compromising on the quality of staff employed, a shortage of staff may mean that managers reduce the level or type of services offered to communities. For example, while a number of benefits result from the provision of outreach services, including improved patient engagement [47-49], healthcare services are not always able to afford the upfront costs required to implement and sustain these services [50, 51]. The ability to tailor services to meet the individual needs of each community in order to improve access to care for marginalised communities [52] has also been hampered by a lack of resources. When funding limitations, rather than the potential benefits associated with the provision of a comprehensive primary healthcare service, determine the availability and quality of care, both providers and patients suffer as healthcare services are overwhelmed by the need to balance high demand with insufficient resources.

Provider Fatigue – Stress, Distress and Burnout

Healthcare provider stress and burnout has been acknowledged as a concern by a number of international studies [53-55]. Similar to findings from this study, a recent Australian report found that staff working in the healthcare and community service sector were at a significant risk of psychosocial ill health [56]. Key stressors for the healthcare sector were thought to emanate from attempting to balance extremely high workloads with dwindling resources.

Caring for chronically ill patients, particularly when the healthcare practitioner has a close personal relationship with the patient, may result in prolonged distress for care providers [53]. Referred to as emotional labour [57], healthcare practitioners may respond to this type of stress in a number of ways. In our study, a small number of practitioner participants spoke about operating in what could be termed survival mode – for example, providing nothing more than a basic level of care while at the same time recognising the need to do more for their patients. Others continued to struggle with the sense of responsibility that came from being unable to meet the needs of the communities they served. Whatever coping strategy was used, the burden of emotional labour can manifest as feelings of exhaustion, hopelessness and psychological distress for the healthcare practitioner [53] and, as some participants noted, as a decrease in the level or quality of service for their patients.

Aboriginal and Torres Strait Islander healthcare providers often deal with another layer of stress associated with simultaneously being members of the Aboriginal and Torres Strait Islander communities they serve. In this sense, Aboriginal and Torres Strait Islander staff often need to bridge two worlds. A study by Roche et al. [58] identified three areas that added to the pressure that Aboriginal and Torres Strait Islander staff faced on a daily basis. The first related to community expectations and obligations which often went far beyond what was expected from their non-Indigenous colleagues. Aboriginal and Torres Strait Islander healthcare workers frequently felt they were expected to respond to community concerns at any hour of the day and night and, therefore, found it difficult to separate work from leisure. The second concern identified within the study by Roche et al. was that Aboriginal and Torres Strait Islander staff reported increased workloads within the healthcare service because non-Indigenous staff often transferred particularly difficult cases to Aboriginal and Torres Strait Islander healthcare workers. A lack of professional advancement opportunities, poor wages and a lack of clearly defined roles also added to the workplace stressors specific to Aboriginal and Torres Strait Islander staff. Finally, Roche et al. acknowledged that Aboriginal and Torres Strait Islander staff were not immune to the loss, grief and historical trauma experienced by others in their communities. Despite having to deal with these stressors, participants in Roche's study also acknowledged the satisfaction they received from serving their communities, as well as the close family and community bonds which supported them through the difficult times, a result that is similar to findings in the KQS monographs one, two and three (www.kvc.org.au).

Resilience Despite the Challenges

From all accounts, many healthcare services were able to continue to provide appropriate and effective care despite this sense of individual and organisational fatigue. Establishing connections with other services and local communities, having the right staff, including strong leaders, and promoting a flexible delivery model all appeared to be central for those services that were able to cope within this difficult and demanding environment.

Linking with other partner organisations was particularly important for broadening the types of services that healthcare providers were able to offer patients. While often dependent on the networking skills of leaders to organise, these collaborations may result in the mobilisation of resources that would otherwise not have been fully utilised [59]. The vast number of ACCHOs have already established relationships with their local hospitals [20]. Links with other mainstream services, including specialist and allied healthcare providers, as well as organisations providing housing and economic support, are being strengthened by healthcare services. These types of collaborations can be particularly advantageous in cases where a patient's wellbeing is affected by the social determinants of health. Collaborations are, however, often easier to establish in urban centres where a number of government and non-government agencies are situated [39]. Remote and even regional services may be disadvantaged due to the lack of potential partners within their immediate region. Opportunities for connecting with other services may also be hampered by staff who are unaware of their existence or situations in which no formal processes for inter-service collaboration exist [16].

Engaging with communities was a key strategy used by a number of services in our study to identify and then prioritise local healthcare needs. As well as empowering people to manage their own health, maximising community involvement can lead to locally appropriate and sustainable interventions [60, 61]. Therefore spending time with communities, listening to their points of view, identifying problems and providing opportunities to learn about solutions can be beneficial [62]. The sense from participants in this study was that engaging with the community was not only in keeping with health services' mission and values, but also that communities were a resource that can directly contribute to managing healthcare services effectively.

Having the right staff on board was another factor that contributed to the ability of the healthcare service to respond to this demanding environment. While a number of other monographs in this series (www.kvc.org.au) have explored the importance of having the right staff on board, the emphasis on the role of leaders and champions in this monograph was a newly-emerging theme. Strong leadership underpinned the success of the healthcare services in this study by supporting staff, liaising with communities and driving change, when needed. Services that had such a person or people on board were considered to be especially fortunate. According to Gardner et al. [63], qualities of effective healthcare leaders include having a clear vision for the organisation's future, as well as the interest, expertise and enthusiasm to make it happen. Most importantly, it requires people skills: the ability to draw people together into a team that can work together to realise the vision of the healthcare service.

Similar to other studies [64, 65], participants spoke of the particular benefits associated with having Aboriginal and Torres Strait Islander peoples in leadership roles. Aboriginal and Torres Strait Islander leaders understand how the system works, how to get the most out of the available resources, and how to talk to and work with communities. Challengingly, the Aboriginal and Torres Strait Islander peoples who tend to take up key leadership positions are often serving in a number of other capacities. This was borne out in our study, with concerns that there may be few candidates who could take up the mantle once the current leader was no longer available. This further highlights the need for capacity-strengthening amongst Aboriginal and Torres Strait Islander peoples [40], not only to develop frontline healthcare practitioners' skills but also those of administrators in order to

increase Aboriginal and Torres Strait Islander representation on boards and committees, as well as within senior management and clinical leadership roles.

While flexibility was believed to be crucial for coping with a demanding healthcare environment, this required careful planning. The leader's role in recognising the need for new ways of thinking to meet changing demands, as well as the fortitude to develop strategies and shepherd through the implementation process, is particularly important [66]. Participants acknowledged a need for flexibility in the ways in which care is delivered so as to best respond to the specific needs identified within their communities. For many Aboriginal and Torres Strait Islander communities, especially those with complex needs, competing priorities or limited resources, some ways in which healthcare services can support access to healthcare include providing transport assistance [67], after hours services [68], outreach activities and home visits [11, 69]. Our study also identified the importance of providing walk-in services rather than requiring appointments, or even providing a combination of these two styles of service delivery, as additional approaches that can be utilised by healthcare services to ensure that they are able to respond to the specific needs of their communities [69].

Opportunities to Reduce Negative Consequences for Patients and Providers

Encouragingly, like Roche et al. [58], this monograph demonstrates that healthcare providers often possess a strong sense of resilience, choosing to look at what can be achieved rather than what cannot. Celebrating small yet very important achievements, such as the rapport and relationships that practitioners built with patients, which provided the impetus to carry on despite the ups and downs of working life, has been reflected in the previous monographs in this series (www.kvc.org.au). This may not, however, be sustainable over the long term. Therefore, to avoid the possibility of eventual burnout, there needs to be change at the systems-level to develop strategies to support individuals who work in these types of environments. Some strategies that can reduce stress and support the wellbeing of healthcare providers include streamlining internal administrative processes and implementing internal mentoring and debriefing sessions, especially around issues of grief and loss, thus allowing staff to engage with patients on their own terms [58].

While it is important to support all staff, it is especially important to ensure that Aboriginal and Torres Strait Islander healthcare staff are provided with specific support to assist in coping with their additional burden of responsibility as a consequence of their community obligations [70]. For example, Aboriginal and Torres Strait Islander staff members may be supported by healthcare services that acknowledge the unique role such staff members have in understanding the dynamics of their communities and, therefore, include Aboriginal and Torres Strait Islander staff in setting healthcare priorities and making decisions within the primary healthcare service [68, 71]. Actively seeking Aboriginal and Torres Strait Islander staff members' advice can also give context to the circumstances of patients, their families and their communities, which may influence the ways in which healthcare should be provided in that setting [72, 73]. This may result in more effective and coordinated healthcare provision.

In order to provide the types of services that Aboriginal and Torres Strait Islander peoples require, there may be a need for structural, systems-level, and funding changes to ensure health services can better meet the needs of people with chronic disease. This is especially important given the high burden of chronic disease faced by some communities. In particular, Aboriginal Community Controlled Health Organisations will need a stable funding base [74]. Secure, flexible funding would

also allow ACCHOs to at least match the staff salaries being offered by mainstream services, encouraging more healthcare providers to apply for these positions. Secure funding would also allow healthcare services to increase the number of Aboriginal and Torres Strait Islander staff positions within a healthcare service, a factor that was considered important by both community and provider-participants in this study. Secure funding could also support activities to enhance the retention of Aboriginal and Torres Strait Islander staff by offering ongoing professional development and additional leave for cultural obligations [58].

The consequences of operating with limited resources may be lessened for both patients and providers if healthcare services supported coordination with other services. Setting up formal relationships with and providing information to staff about external healthcare services and non-healthcare services that may address the social determinants of health could reduce the burden on staff who may be feeling unable to address contextual factors within their working day [75]. Establishing multi-disciplinary teams that can meet a variety of patient needs is another strategy for both sharing the burden upon healthcare staff and providing care that is acceptable and effective for communities [11, 76].

Strengths and Limitations

Broad strengths and limitations of this research have been previously described in Monograph One of this series. One of the primary strengths of the KQS 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, and heart and kidney disease. In addition, 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. 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.

Conclusions

Many healthcare providers have an understanding of how to provide effective and acceptable care for Aboriginal and Torres Strait Islander peoples living with chronic disease. However, they can face a number of obstacles when doing so. High levels of chronic disease together with a complex healthcare system, leaves many healthcare providers physically and emotionally stressed. Funding constraints, high employee turnover and shortages of other resources further reduces the ability of services to support not only their patients, but also their staff. In some circumstances, healthcare service managers and practitioners are forced to make difficult and ethically challenging decisions, adding to their already high levels of stress. Ultimately, the cost can include a reduction in the quality of healthcare that practitioners are able to provide.

Encouragingly, many healthcare providers demonstrate a strong sense of resilience. Linking with other services and engaging strong leaders who embody qualities such as understanding, empathy, openness and the ability to learn from past mistakes can support this resilience. Yet strong

leadership does not in itself replace the need for a secure long-term funding stream or the need for effective systems which support staff working within healthcare services. Nor does it take away from the opportunities that come from building relationships and collaborating with other healthcare and non-healthcare services. These relationships can reduce the burden on healthcare services by supporting the prevention of chronic disease, as well as the provision of health promotion more generally. Healthcare services that choose not to, or are unable to collaborate with other services may be missing out on a resource that could support the quality of care provided for Aboriginal and Torres Strait Islander peoples living with chronic disease.

References

1. Government of Australia, *Improving primary health care for all Australians*. 2011, Government of Australia: Canberra.
2. Australian Medical Association, *General practice in primary care: Responding to Patient Needs*. 2008.
3. Department of Health and Ageing, *Primary health care reform in Australia: Report to support Australia's first national primary health care strategy*. 2009, Department of Health and Ageing: Canberra.
4. Wiese, M., et al., *Australia's systems of primary healthcare - the need for improved coordination and implications for medicare Locals*. *Australian Family Physician*, 2011. **40**(12): p. 995-999.
5. Rogers, W. and B. Veale, *Primary health care and general practice*. 2000, Department of General Practice, Flinders University: Bedford Park.
6. Tsey, K., et al., *The role of empowerment through life skills development in building comprehensive primary health care systems in Indigenous Australia*. *Australian Journal of Primary Health*, 2005. **11**(2): p. 16-25.
7. Irwan, A. and E. Scali, *Action on the Social determinants of health: Learning from previous experiences. Social determinants of health discussion paper 1*. 2010, World Health Organization: Geneva.
8. Standing Council on Health, *National primary health care strategic framework*. 2013, Commonwealth of Australia: Canberra.
9. Keleher, H., *Why primary health care offers a more comprehensive approach to tackling health inequities than primary care*. *Australian Journal of Primary Health*, 2001. **7**(2): p. 57-61.
10. Dwyer, J., et al., *The overburden report: contracting for Indigenous health services*. 2009, Cooperative Research Centre for Aboriginal Health: Darwin.
11. McDonald, J., et al., *Collaboration across private and public sector primary health care services: benefits, costs and policy implications*. *Journal of Interprofessional Care*, 2011. **25**: p. 258-264.
12. Department of Health and Ageing, *Primary health care reform in Australia. Report to support Australia's first national primary health care strategy*. 2009, DoHA: Canberra.
13. Kerber, K.J., et al., *Continuum of care for maternal, newborn and child health: from slogan to service delivery*. *Lancet*, 2007. **370**(1358-69).
14. Davies, G.P., et al., *Integrated primary health care in Australia*. *International Journal of Integrated Care*, 2009. **9**(14): p. www.ijic.org.
15. Davies, G.P., et al., *Coordinating primary health care: an analysis of the outcomes of a systematic review*. *Medical Journal of Australia*, 2008. **188**: p. S65-S68.
16. Anjou, M.D., A.I. Boudville, and h.R. Taylor, *Local co-ordination and case management can enhance Indigenous eye care - a qualitative study*. *BMC Health Services*, 2013. **13**(255).
17. Australian Institute of Health and Welfare, *Australia's health*. 2010, AIHW: Canberra.

18. Wakerman, J., et al., *Primary health care delivery models in rural and remote Australia - a systematic review*. BMC Health Services, 2008. **8**(276): p. doi: 10.1186/1472-6963-8-276.
19. Australian Institute of Health and Welfare, *Rural, regional and remote health: Indicators of health*. 2005, AIHW: Canberra.
20. Australian Institute of Health and Welfare, *Access to health services for Aboriginal and Torres Strait Islander people*. 2011, AIHW: Canberra.
21. Johanson, P.R., *Indigenous health. A role for private general practice*. Australian Family Physician, 2011. **40**(1/2): p. 16-19.
22. National Aboriginal Community Controlled Health Organisation. *Vision and principles*. 2013 [cited 2014 14th March]; Available from: <http://www.naccho.org.au/about-us/vision-and-principle/>.
23. Department of Health and Ageing, *Aboriginal & Torres Strait Islander Health Performance Framework. 2012 Report*. 2012, Department of Health and Ageing: Canberra.
24. Liaw, S.T., et al., *Successful chronic disease care for Aboriginal Australians requires cultural competence*. Australian and New Zealand Journal of Public Health, 2011. **35**(3): p. 238-248.
25. Department of Health and Ageing, *The Aboriginal and Torres Strait Islander Coordinated Care Trials - National evaluation report (Volume 1) - Main Report*. 2001, Commonwealth of Australia: Canberra.
26. Rosewarne, C. and J. Boffa, *An analysis of the Primary Health Care Access Program in the Northern Territory: A major Aboriginal health policy reform*. Australian Journal of Primary Health, 2004. **10**(3): p. 89-100.
27. Kelaher, M., et al., *Evaluation of PBS medicine supply arrangements for remote area Aboriginal health services under S100 of the National Health Act*. 2004, Co-operative Research Centre for Aboriginal Health and Program Evaluation Unit, University of Melbourne: Melbourne.
28. Department of Human Services. *Indigenous Health*. 2013 3rd March 2013]; Available from: <http://www.medicareaustralia.gov.au/provider/patients/indigenous.jsp>.
29. Econtech Pty Ltd, *Costing models for Aboriginal and Torres Strait Islander health services*. 2004, Department of Health and Ageing: Canberra.
30. Beaver, C. and Y. Zhao, *Investment analysis of the Aboriginal and Torres Strait Islander Primary Health Care Program in the Northern Territory*. 2004, Australian Department of Health and Ageing: Canberra.
31. Dwyer, J., et al., *The overburden report; contracting for Indigenous health services*. 2009, flinders University and Cooperative Research Centre for Aboriginal Health: Cairnina, Northern Territory.
32. Anderson, I., *Mutual obligation, shared responsibility agreements and Indigenous health strategy*. Australian and New Zealand Health Policy, 2006. **3**(10): p. doi:10.1186/1743-8462-3-10.
33. Australian Bureau of Statistics, *Australian Standard Geographical Classification (ASGC)*. 2010.
34. Kleinman, A., L. Eisenberg, and B. Good, *Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research*. Focus, 2006. **IV**(1): p. 140-149.
35. Nettleton, S., *The sociology of health and illness*. 2nd ed. 2008, Cambridge: Polity Press.
36. Alford, K., *Comparing Australian with Canadian and New Zealand Primary Care Health Systems in Relation to Indigenous Populations: Literature Review and Analysis*. 2005, Onemda VicHealth Koori Health Unit: Melbourne.
37. Dwyer, J., et al., *Contracting for Indigenous Health Care: Towards Mutual Accountability*. Australian Journal of Public Administration, 2011. **70**(1): p. 34-46.
38. Beaver, C. and Y. Zhao, *Investment analysis of the Aboriginal and Torres Strait Islander Primary Health Care Program in the Northern Territory*. 2004, Australian Department of Health and Ageing: Canberra.

39. Baeza, J. and J.M. Lewis, *Indigenous health organizations in Australia: Connections and capacity*. International Journal of Health Services, 2010. **40**(4): p. 719-742.
40. Baeza, J., R. Bailie, and J.M. Lewis, *Care for chronic conditions for Indigenous Australians: Key informants' perspectives on policy*. Health Policy, 2009. **92**: p. 211-217.
41. Lopez, A., et al., *Global and regional burden of disease and risk factors*. The Lancet, 2001. **367**: p. 1745 - 57.
42. Zhao, Y., et al., *Cost estimates of primary health care activities for remote Aboriginal Communities in the Northern Territory*. Department of Health and Community Services, Northern Territory: Casuarina, NT.
43. Booth, B.J., N. Zwar, and M.F. Harris, *A complexity perspective on health care improvement and reform in general practice and primary health care*. Australian Journal of Primary Health, 2010. **16**: p. 29 - 35.
44. Enns, C. and D. Gregory, *Lamentation and loss; expressions of caring by contemporary surgical nurses*. Journal of Advanced Nursing, 2007. **58**(4): p. 339-347.
45. Sawatzky, J.-A.V. and C. Enns, *Exploring the key predictors of retention in emergency nurses*. Journal of Nursing Management, 2012. **20**: p. 696-707.
46. Simpson, C. and F. McDonald 'Any body is better than nobody?' *Ethical questions around recruiting and/or retaining health professionals in rural areas*. Rural and Remote Health, 2011. **11**.
47. Gruen, R.L., T.S. Weeramanthri, and R. Bailie, *Outreach and improved access to specialist services for indigenous people in remote Australia: the requirements for sustainability*. Journal of Epidemiology & Community Health, 2002. **56**: p. 517-521.
48. Gruen, R.L., et al., *Specialist outreach to isolated and disadvantaged communities; A population-based study*. The Lancet, 2006. **368**(9530): p. 130-138.
49. Moffatt, M.E. and C. Cook, *How can health community foster and promote the health of Aboriginal children and youth?* Paediatrics & Child Health, 2005. **10**(9): p. 549-552.
50. Rygh, E.M. and P. Hjortdahl, *Continuous and integrated health care services in rural areas. A literature study*. Rural and Remote Health, 2007. **7**(776).
51. Gruen, R.L., et al., *Specialist outreach clinics in primary care and rural hospital settings. (Review)*. Cochran Library, 2009(1).
52. Browne, A.J., et al., *Closing the health equity gap: evidence-based strategies for primary health care organizations*. International Journal of Health Equity, 2012. **11**(59).
53. Dollard, M.F., et al., *Job stress in the Australian and international health and community services sector: A review of the literature*. International Journal of Stress Management, 2007. **14**(4): p. 417-445.
54. van der Ploeg, E., S.M. Dorresteyn, and R.J. Kleber, *Critical incidents and chronic stressors at work: Their impact on forensic doctors*. Journal of Occupational Health Psychology, 2003. **8**: p. 157-166.
55. Bakker, A.B., et al., *Effort-reward imbalance and burnout among nurses*. Journal of Advanced Nursing, 2000. **31**: p. 884-891.
56. Dollard, M.F., et al., *The Australian workplace barometer: Report on psychosocial safety climate and worker health in Australia*. 2012, University of South Australia, Centre for Applied Psychological Research: Adelaide.
57. Hochschild, A.R., *The managed heart: commercialisation of human feeling*. 1983, Berkeley: University of California Press.
58. Roche, A.M., et al., *Sharing stories: Indigenous alcohol and other drug workers' well-being, stress and burnout*. Drug and Alcohol Review, 2013. **32**: p. 527-535.
59. Gardner, K.L., et al., *Understanding uptake of continuous quality improvement in Indigenous primary health care: lessons from a multi-site case study of the Audit and Best Practice for Chronic Disease project*. Implement Sci, 2010. **5**: p. 21.

60. Wiggins, N., *Popular education for health promotion and community empowerment: a review of the literature*. Promotion International, 2011. DOI: 10.1093/heapro/dar046.
61. Jennings, W., G. Spurling, and D. Askew, *Yarning about health checks: barriers and enablers in an urban Aboriginal medical service*. Australian Journal of Primary Health, 2014. 20: p. 151-157.
62. Constable, S.E., et al., *Approaches to dog health education programs in Australian rural and remote Indigenous communities: four case studies*. Health Promotion international, 2012. 28(3): p. 322-332.
63. Gardner, K.L., et al., *Understanding uptake of continuous quality improvement in Indigenous primary health care: lessons from a multi-site case study of the Audit and Best Practice for Chronic Disease project*. Implementation Science, 2010. 5(21).
64. Australian Institute of Health and Welfare, *What works to overcome Indigenous disadvantage: Key learning and gaps in the evidence 2010-11*. 2012, Australian Institute of Health and Welfare: Canberra.
65. Humes, G. and N. Carolyn, *Turmoil, survival and stability - the journey of an Aboriginal medical service*, in *Standing up for Rural Health: Learning from the past. Action for the Future*. 2007: Albury, NSW.
66. Lynas, K., *Leadership scheme to develop the careers of talented candidates*. Nursing Management, 2012. 18(9): p. 34-36.
67. Mills, D., et al., *Eyre Peninsula chronic disease self management project for Aboriginal communities in Ceduna/Koonibba and Port Lincoln*. 2003, Port Lincoln Aboriginal Health Services, Ceduna Koonibba Aboriginal Health Service, Eyre Peninsula Division of General Practice: Bedford Park.
68. Menzies School of Health Research, *Sentinel Sites Evaluation Final Report*. 2013, Menzies School of Health Research: Darwin, NT.
69. Govil, D., et al., *Identifying culturally appropriate strategies for coronary heart disease secondary prevention in a regional Aboriginal Medical Service*. Aust J Prim Health, 2013.
70. Mitchell, M. and L.M. Hussey, *The Aboriginal health worker*. The Medical Journal of Australia, 2006. 184(10): p. 529-530.
71. Gordon, R., et al., *The Walgan Tilly Project: Chronic Care for Aboriginal People*. 2008, PriceWaterhouseCoopers.
72. Battersby, M.W., et al., *Research implementing the Flinders Model of Self-management Support with Aboriginal people who have diabetes: findings from a pilot study*. Australian Journal of Primary Health, 2008. 14(1): p. 66-74.
73. Wade, V., D. Jackson, and J. Daly, *Coronary heart disease in Aboriginal communities: towards a model for self-management*. Contemporary nurse, 2003. 15(3): p. 300-309.
74. Hoy, W., *"Closing the gap" by 2030: aspiration versus reality in Indigenous health*. Medical Journal of Australia, 2009. 190(10): p. 542-544.
75. Si, D., et al., *Assessing health centre systems for guiding improvement in diabetes care*. BMC Health Services Research, 2005. 5(1): p. 56.
76. Gordon, R., et al., *Chronic Care for Aboriginal People Model of Care*. 2010, NSW Department of Health: North Sydney.