‘I’m not sure it paints an honest picture of where my health’s at’ – identifying community health and research priorities based on health assessments within an Aboriginal and Torres Strait Islander community: a qualitative study

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Abstract. Aboriginal and Torres Strait Islander health assessments are conducted annually in Australian primary care to detect risk factors, chronic diseases and implement preventive health measures. At the Inala Indigenous Health Service, health assessment data have also been used for research purposes. This research has been investigator-driven, which risks misinterpreting or ignoring community priorities compared with community-led research. The objective of this research was to learn about the Aboriginal and Torres Strait Islander community’s health priorities that could be translated into research themes, and investigate these using health assessment data. A thematic analysis of data was conducted from 21 semi-structured interviews with purposively selected key informants from an urban Aboriginal and Torres Strait Islander community. Key informants articulated an authoritative understanding of how interrelated, inter-generational, social, cultural and environmental determinants operated in a ‘cycle’ to influence the community’s health. Key informant views supported the inclusion of these determinants in health assessments, reinforced the importance of comprehensive primary healthcare and strengthened referral pathways to community resources. Some key informants were ambivalent about Aboriginal and Torres Strait Islander health assessments because of their biomedical emphasis. This research also revealed limitations of health assessment-based research and the biomedical emphasis of the health system more broadly.

Introduction

Current national strategies to improve health outcomes, including life expectancy for Aboriginal and Torres Strait Islander peoples, are failing to meet their targets (Australian Government 2016). This failure may be due, in part, to the lack of research to inform strategies to improve health in urban areas (Eades et al. 2010), the setting where the majority of Aboriginal and Torres Strait Islander people live (Australian Bureau of Statistics 2013) and where most disease burden is experienced (Australian Institute of Health and Welfare 2016). High-quality, community-level research data are required to inform program delivery and advocacy (Biddle 2014).

One way to address the lack of research data is to use computerised Aboriginal and Torres Strait Islander health assessment (HA) data designed for dual clinical and research purposes (Spurling et al. 2013). Investigator-driven, HA-based published research papers at the Inala Indigenous Health Service (IIHS) have reflected investigator inclinations and the biomedical emphasis of HAs (Spurling et al. 2013). The biomedical model sees health as primarily about medical practitioners detecting and curing diseases in individuals (Lewis 2005). However, rather than a preoccupation with diseases and their risk factors, the National Aboriginal Health Strategy Working Party emphasised the importance of social and cultural
determinants in its holistic definition of health for Aboriginal and Torres Strait Islander peoples (National Aboriginal Health Strategy Working Party 1989). Investigator-driven research, not conducted in consultation with the community, may waste resources, misinterpret priorities, or worse, represent an extension of colonial control causing further trauma (Monk et al. 2009). This research aimed to identify the priority health issues of the Inala Aboriginal and Torres Strait Islander community, and which of these might be translated into research questions answerable using computerised HA data.

**Methods**

We situated this research in the transformative paradigm, which assumes that knowledge reflects power and social relationships within society, and seeks to improve the social world by privileging oppressed peoples’ voices rather than silencing or overlooking them (Mertens 2009).

**Participants and data collection**

C. I. Kirk and C. J. Bond used their community links to identify key informants with knowledge of the community’s health concerns. Key informants included members of community-controlled or State-run organisations working in Inala to improve the health and/or social world of Aboriginal and Torres Strait Islander community members in Inala, and respected local Aboriginal and Torres Strait Islander elders. Purposeful sampling of key informants was designed to include a mix of both Aboriginal and Torres Strait Islander ethnicities, male and female genders and a range of ages working in diverse organisations with an interest in the health and well-being of Aboriginal and Torres Strait Islander peoples in Inala. We aimed to interview sufficient key informants to achieve data saturation, such that we could be reasonably confident that the inclusion of additional key informants was unlikely to produce new themes (Guest et al. 2006).

Between February and June 2013, C. I. Kirk contacted potential participants by telephone, text or in person. G. K. Spurling, a non-Indigenous medical doctor who has worked at the IIHS for over 10 years, conducted face-to-face, semi-structured interviews with consenting participants as part of his doctoral research. Care was taken to not replicate the power structures of a medical consultation by conducting interviews away from the clinical setting. Depending on participant preference, interviews were conducted in the participants’ workplace, the non-clinical sectors of the IIHS, and in one case, in the participant’s home. An interview guide and one page summary of health categories contained in HAs for children, adults, people with type 1 or type 2 diabetes mellitus and pregnant women was used to facilitate discussion regarding the role of HAs and key informants’ health priorities for research using HA information. Consistent with semi-structured interview methods, some participants used the interview guide to prompt their thinking, and others spoke about their health priorities without reference to the guide. Interviews lasted between 30 min and 2 h, were audi-taped, transcribed, and interview notes were taken. Each interviewee received a A$25 gift voucher for participating.

**Analysis**

Transcribed interview data were uploaded to NVivo 9 (QSR International, Melbourne, Vic., Australia) software, which was used to assist data management. One investigator (G. K. Spurling) used thematic analysis (Braun and Clarke 2006) to code and categorise transcribed data and interview notes, and discussed the identification and development of themes with the other authors at regular meetings. The broad categories of health priorities based on HA information and attitudes to HAs were anticipated *a priori*. Our interpretation of the data was fed back to key informants and other community members at informal meetings, by telephone, at a community seminar and to the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research (ICJ) (Bond et al. 2016). Community members’ responses, comments and questions at these feedback sessions supported our interpretation of interview responses.

**Ethics approval and community oversight**

The study was supported by the ICJ and approved by the Queensland Health Metro South Human Research Ethics Committee at the Princess Alexandra Hospital and the University of Queensland’s Behavioural and Social Sciences Ethical Review Committee. All participants provided written informed consent before being interviewed. All quotes were attributed to pseudonyms and care was taken to avoid identification of participants.

**Results**

Twelve men and nine women took part in the interviews, with a range of ages (Table 1). No-one who was approached to be interviewed declined. After 21 interviews, we felt data saturation had been achieved. The task of identifying a list of discrete health research priorities from the HAs was not achieved. Rather, deeper understandings of health and illness beyond HA content were elicited from participants. The three central themes that emerged included: (1) complex, interrelated, intergenerational nature of health involving social, cultural and environmental determinants of health (SCEDH); (2) ambivalence about HAs; and (3) community strength.

**Complex, interrelated, intergenerational nature of health involving SCEDH**

Male and female key informants of all ages, demonstrated an authoritative understanding, consistent with their lived
Participants of male and female genders and all ages described the nature of intergenerational and social disadvantage. The resulting hopelessness and intergenerational effects combined to impede young people in an interrelated cycle, circle or chain to in many domains of life. Members of her family and community described about the positive health consequences of employment for interacting in their community. For example, Lily was unreserved in sharing her experience, of the complex cycle of interrelated SCEDH operating in her life.

In adolescence, key informants also spoke of how peer influences and negative social media experiences frequently combined to impede young people’s educational potential. Grace described the resulting hopelessness and intergenerational nature of ‘the cycle’:

...you just see it, all these young kids going to little parties and drinking on weekend ... they start missing school, they fall behind, they don’t finish high school, they don’t have the qualifications to get a job... So they turn to crime, and then drugs in the school and their kids are going to do the same because they don’t have somebody to look up to. So that’s the cycle [Grace].

In addition to educational and employment difficulties, participants of male and female genders and all ages described disempowering and traumatic experiences of institutional racism in their interactions with social services and the police:

I’ve been pulled over [by police] and spoken to like I’m nothing. I think that impacts especially on young people [Noah].

They mightn’t get enough sleep because they’re not sleeping in their own house. The family don’t have their own family routine, so it effects the school work... [Mia].

Ambivalence towards HAs

Most key informants had had a HA with only two saying they had never had one. Key informants’ experience of Aboriginal and Torres Strait Islander HAs were mixed, as four key informants gave unqualified support for the capacity of HAs to detect medical problems early.

I think the health checks are really important for Aboriginal and Torres Strait Islander people... because some people feel shame to go to the doctor, and if they leave it too long there could be a problem building in their body [Liam].

However, a similar number of mostly younger key informants commented on the time-consuming nature of HAs. Another key informant was concerned about the centrality of chronic disease risk factors and illness in HAs, and suggested that the health service could engage better with SCEDH. In the context of a discussion about the effect of confidence and SCEDH, Edward felt that HA content was superficial and did not get to the heart of peoples’ health problems:

I’m not sure whether it paints a really honest picture of exactly where my health’s at. I think that [it] probably can go a bit more in depth [Edward].

Participants’ responses suggested that their view of health and the social world was not adequately covered by HAs, which measured health in a compartmentalised, disease-focussed way. For example, Bradley felt doctors and HAs were unlikely to help with his past concerns about identity, a social issue central to his health:

I don’t see how a doctor is going to solve an identity crisis. It’s a social thing... [Bradley].

In this environment of institutional racism, the mental health consequences for young people leaving high school without a qualification or employment were bleak. Many key informants were concerned that mental health issues were undiagnosed in the community, and that this untreated burden of depression would lead to unexpected suicide with devastating, community-wide effects:

If I had to put one at the top of the list, it would have to be mental health because it’s really a silent killer [Steven].

The resulting grief from premature death and especially suicide was seen as a huge issue for the community. This concern was more likely to be expressed by female key informants:

Well, I just see the end result of people who have lost somebody close and how it impacts their work, how it impacts them socially... and often people in the community forget about the young ones that have lost their auntie, uncle [Lily].

Female key informants were also more likely than males to suggest that more support was required to assist community members navigate challenging elements of the cycle like grief, single parenthood, unemployment and household crowding.

### Table 1. Characteristics of Aboriginal and Torres Strait Islander community stakeholders (n = 21)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participants (n)</th>
<th>(%)</th>
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<tbody>
<tr>
<td>Ethnicity</td>
<td></td>
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</tr>
<tr>
<td>Aboriginal</td>
<td>16 (76)</td>
<td></td>
</tr>
<tr>
<td>Torres Strait Islander</td>
<td>5 (24)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>12 (57)</td>
<td></td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
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<tr>
<td>&lt;30</td>
<td>5 (23)</td>
<td></td>
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<tr>
<td>30–49</td>
<td>9 (43)</td>
<td></td>
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<tr>
<td>50+</td>
<td>7 (33)</td>
<td></td>
</tr>
<tr>
<td>Employed by</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community-controlled organisation</td>
<td>6 (29)</td>
<td></td>
</tr>
<tr>
<td>Other community-based organisation</td>
<td>3 (14)</td>
<td></td>
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<tr>
<td>Inala Indigenous Health Service</td>
<td>4 (19)</td>
<td></td>
</tr>
<tr>
<td>Other state-run organisation</td>
<td>3 (14)</td>
<td></td>
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<tr>
<td>Elders</td>
<td>5 (24)</td>
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Community strength

The personal stories told by participants were all ones of strength, as they continued to navigate the challenges of ‘the cycle’ to take on meaningful, important roles within the Inala Aboriginal and Torres Strait Islander community. Participants described how their health depended on the support of parents, family members and positive peer groups. After describing the negative features of ‘the cycle’ for high school students, Grace talked about how family support had been a crucial element for the group of students in her year who had graduated:

We weren’t rich, we weren’t really wealthy, we were average . . . but I had that support from my family as well . . . that’s why we graduated [Grace].

Not only was support crucial at home and in the family, participants expressed positivity about the connectedness and cultural richness of the Inala Aboriginal and Torres Strait Islander community:

There was something strong about the community that I think was a protective factor [Olivia].

The IIHS was also seen as an important component of the community’s well-being and self-esteem. Positive comments about the IIHS made by participants may have been more likely because the interviewer was a well-known doctor at this service. However, the health service was clearly an important, trusted part of participants’ lives in the community:

They care. [The IIHS] is one of the best organisations I’ve been around . . . I love the treatment they give you [Gregory].

Discussion

Key informants gave confident, authoritative accounts of the centrality of SCEDH to the health of the community. These accounts were consistent with the holistic Aboriginal definition of health, which is not merely the provision of doctors or absence of disease, but involves all aspects of life including grief and loss, a sense of hopelessness and being caught in the cycle of SCEDH (National Aboriginal Health Strategy Working Party 1989). Other studies involving interviews with Aboriginal peoples also found SCEDH were central to health; this included the historical legacy of colonisation, experiences of racism and reduced socioeconomic opportunities (Priest et al. 2012; Waterworth et al. 2016).

The ‘cycle’ articulated by key informants in this study has similarities with the life course theory of social determinants, whereby stressors accumulate across the life course at critical, vulnerable, life transitions (Blane 2006). Adverse experiences in childhood, such as socioeconomic deprivation, are associated with several health problems in adulthood, including ischaemic heart disease, depression, substance use, type 2 diabetes mellitus and premature death (Finch and Crimmins 2004; Power et al. 2013). For Aboriginal and Torres Strait Islander peoples, the life course and ‘the cycle’ are negatively influenced by ongoing colonisation and institutional racism (Carson et al. 2007).

Key informants’ ambivalence towards HAs implies a disjunction between the risk factor and disease emphasis of HAs and the complex cycle of interrelated SCEDH lived by key informants. This disjunction suggests limitations for policies informed by the biomedical model of health, especially given current strategies are failing to meet their targets for health outcomes for Aboriginal and Torres Strait Islander peoples (Australian Government 2016). For researchers, in addition to an inadequate quantity of health research addressing the health needs of Aboriginal and Torres Strait Islander peoples in urban areas (Eades et al. 2010), this disjunction suggests that research needs to have a greater emphasis on the SCEDH reflecting key informant priorities.

Although participant concerns were largely situated in a social and policy world, which some may argue is beyond the scope of primary healthcare, this sector can play an important role in addressing social determinants of health (Baum et al. 2013). At the IIHS, this research has supported inclusion of additional questions regarding SCEDH in HAs, consistent with the principles of comprehensive primary healthcare articulated by the Declaration of Alma-Ata (World Health Organization 1978). One of the authors of this paper, C. J. Bond, an Aboriginal community member, suggested the addition of these questions before the conduct of the interviews described here, but these questions did not form part of HAs at the IIHS until after the interviews had been concluded. The additional questions regarding SCEDH are likely to better identify patient health concerns, reinforce the importance of multidisciplinary comprehensive primary healthcare, which includes social workers and community-based health promotion, and prompt referral to appropriate community resources, which has been found to improve social and emotional wellbeing (Grant et al. 2000). Better understandings of community priorities from this community consultation research, together with the additional questions regarding SCEDH in HAs, have contributed to conversations within the IIHS about how the service can better address SCEDH experienced by our patients, strengthen clinical referrals to the IIHS community team and work more closely with local community-based organisations.

The involvement of Aboriginal community members (C. I. Kirk and C. J. Bond) ensured a wide variety of Inala community key informants with varying perspectives were interviewed, and no-one declined an interview. However, critical theorists would argue that this study would have produced different results with an Aboriginal and/or Torres Strait Islander researcher conducting the interviews, data coding and community feedback (Mathison 1997). The study findings may also have been different had there been an unstructured discussion of health and research priorities, rather than structuring the interviews around HA content. However, the positive reception at community feedback sessions suggests concordance between our findings and key informants’ beliefs and opinions.

Conclusions

Although HAs have a role in individual preventive health, they may be less useful in responding to the complex, interrelated SCEDH that are important to key community informants’ conception of health. Future HA-based IIHS research needs to value the community’s authoritative knowledge regarding the
importance of SCEDH, and recognise the limitations of biomedical and investigator-driven research. The importance of a holistic conception of health including SCEDH is not limited to Aboriginal and Torres Strait Islander peoples in Inala. By conducting a computerised HA, which includes more questions about SCEDH, clinicians in a wide range of primary healthcare settings are more likely to have conversations with their Aboriginal and Torres Strait Islander patients about SCEDH, which are relevant to their patients’ conception of health. In turn, these conversations are likely to lead to the management plan and referrals required to help resolve patient health concerns. These findings also represent a challenge for policymakers to meaningfully address SCEDH as part of a health system, which purports to meet the health needs of Aboriginal and Torres Strait Islander peoples, but continues to prioritise biomedical models of health and health care.

Conflicts of interest

The first author, G. K. Spurling, conducted this study as part of his doctoral research.

References


