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Decolonizing Indigenous health: Generating a productive dialogue to eliminate Rheumatic Heart Disease in Australia

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ABSTRACT (300 WORDS)

In common with colonized Indigenous people worldwide, many Australian Aboriginal people experience inequitable health outcomes. While the commitment and advocacy of researchers and health practitioners has resulted in many notable improvements in policy and practice, systemic and structural impediments continue to restrain widespread gains in addressing Indigenous health injustices. We take Rheumatic Heart Disease (RHD), a potent marker of extreme health inequity, as a case study, and critically examine RHD practitioners' perspectives regarding the factors that need to be addressed to improve RHD prevention and care. This study is an important explanatory component of a broader study to inform new clinical practices, and health system strategies and policies to reduce RHD. A decolonising, critical medical anthropology (CMA) analysis of findings from 22 RHD practitioner in-depth interviews conducted in May 2016 revealed both practitioners' perceptions of health system shortcomings and a sense of hopelessness and powerlessness to transform existing health system inequities, the negative impacts of which were subsequently confirmed in a separate study of RHD patients' lived realities. We reveal how biomedical dominance, normalized deficit discourses and systemic racism influence the current policy and practice landscape, narrowing the intercultural space for productive dialogue and reinforcing the conditions that cause disease. To counter biomedical approaches that contribute to existing health inequities in health care, we recommend localized, strength-based, community-led research projects focused on actions that use critical decolonizing social science approaches to achieve system change. We demonstrate the importance of integrating biological and social sciences approaches in research, education/training, and practice to: 1) be guided by Indigenous strengths, knowledges and worldview, and 2) adopt a critical reflexive stance to examine systems, structures and practices. Such an approach facilitates productive cross-cultural dialogue and social transformation; providing direction and hope to practitioners, enhancing their knowledge, skills and capacity and improving Aboriginal health outcomes.

1. Introduction

The 370 million Indigenous peoples living in over ninety high- and low-income countries globally generally experience substantially higher disease burden and poorer health outcomes compared with benchmark populations (Anderson et al., 2016; UN, 2016). Colonial legacies resulting in transgenerational trauma, grief and loss (Atkinson et al., 2014) play a critical role in a range of inequitable health and wellbeing outcomes (Dudgeon et al., 2020). In Australia, while the commitment and advocacy of many researchers and health practitioners has resulted

in notable improvements in specific health outcomes (Laird et al., 2020), Aboriginal and Torres Strait Islander (hereafter Indigenous / Aboriginal) health generally remains far worse compared with other Australians (AIHW, 2020).

Rheumatic heart disease (RHD) is a potent marker of health inequity in Australia, occurring predominantly in Aboriginal communities. RHD particularly impacts young people, with contemporary age-standardized prevalence 60 times higher in Aboriginal than non-Aboriginal Australian populations <55 years (Katzenellenbogen et al., 2020). RHD is also associated with remote living, with the prevalence in northern and

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central Australia among the highest reported globally (Parnaby and Carapetis, 2010) accompanied by high mortality rates (Colquhoun et al., 2015). Moreover, screening projects demonstrate that current figures substantially underestimate true numbers due to undiagnosed/sub-clinical cases (Francis et al., 2020). The precursor condition to RHD, acute rheumatic fever (ARF), an autoimmune response to common Strep A infections, primarily affects children. Given the young age of disease onset, the high cost of health care and premature deaths from RHD, the burden on individual, family, community and society is high (Ralph et al., 2018).

Despite the dedication of researchers and healthcare practitioners, strategies to date have been largely ineffective in reducing rates of RHD in Indigenous Australians (Cannon et al., 2018; Katzenellenbogen et al., 2020). In November 2020 the NHMRC funded End RHD Centre for Research Excellence (1146525) published *The RHD Endgame Strategy: a blueprint for eliminating RHD* (the Strategy) (Wyber et al., 2020) to address this impasse. This comprehensive report provides a detailed view of the multi-sectorial RHD policy context across all levels of prevention, seeking to inform new clinical practices, health system strategies and policies to radically reduce RHD occurrence and improve care for individuals, families and communities living with RHD. As part of the End RHD CRE a program of work was undertaken focused on the lived experience of RHD in Australia (Haynes, 2021), working with Aboriginal co-researchers to investigate the experiences, perspectives and understandings of Aboriginal people living with RHD (Haynes et al., 2019). The current study forms a component of the End RHD CRE that informed the lived experience study through the perspectives and experiences of RHD practitioners (people with a broad range of roles, experience and practice directly related to RHD care or Aboriginal health).

1.1. Study aim

The current study aims to apply a critical decolonising lens in order to: 1) Analyse the perspectives of RHD practitioners regarding the factors that need to be addressed to improve RHD prevention and care (systemic and environmental); and, 2) Interrogate RHD practitioner discourses to reveal a) the mechanisms that systemically determine/sustain health inequities, and, b) personal and professional implications (reflection on Study aim 2 reported in the Discussion).

This analysis suggests ways to mitigate the limitations of the biomedical and economic rationalist discourses that tend to dominate current RHD policy and practice and impede system change. This in turn can increase the health system's capacity to implement the necessary changes in practice and systems to improve the experiences reported by Aboriginal people living with RHD (Haynes, 2021) as well as broader policy shifts recommended by the Endgame report (Wyber, 2020). The following sections provide the context regarding the dominance of biomedical approaches in the RHD space and the drivers for decolonising this approach.

1.2. Rheumatic heart disease and biomedical dominance

A recent systematic literature review found that much Australian RHD research, including translation into policy and practice, reflected a dominant biomedical system bias (Haynes et al., 2020). Biomedicine predominantly focuses on pathology, located in separate organs or body systems, and treats diseases with minimal consideration of socio-cultural context (Collyer et al., 2017). Fundamental to this approach is a ubiquitous and unquestioned legitimization of biomedicine that is reinforced in the health system: in curriculum and training for healthcare practitioners; health service management; policy and funding; and in clinical practice.

A recent report analyzing the British health system conceptualized the entrenched and unquestioned rightness of biomedicine as a social, political and epistemic "biomedical bubble" (Jones and Wilsdon, 2018: 5) which limits research and policy innovation, further contributing to

health inequalities. The report argues that the sole emphasis on biomedical approaches in healthcare "reflects the power and influence of the biomedical community in shaping research priorities and the allocation of resources ... [through] which supporters of biomedical science create reinforcing networks, feedback loops and commitments" (Jones and Wilsdon, 2018: 5). Thus, the broad diffusion of a biomedical worldview can be a form of social control "based on specific modern regimes of knowledge and practice ... not achieved through coercion but through dissemination of knowledge in an institutionalized form" (Witeska-Młynarczyk, 2015: 386). In the context of Aboriginal health, Indigenous theorists critique the ongoing colonisation inherent in privileging dominant medical narratives and interactions as a superior and more valid form of knowledge (D'Antoine et al., 2019; Dudgeon and Walker, 2015). This dominance is reflected in the tendency to blame Aboriginal people for their poorer health at the expense of examining health system, socio-economic, historical and political factors. The failure to examine structural inequities and dominant discourses results in policies that have, for example, rendered RHD invisible within the WHO priorities for preventative health (Schwartz et al., 2021).

The limitations of a purely biomedical approach to RHD highlighted in the systematic literature review (Haynes et al., 2020), found that nearly half the reviewed publications investigated barriers to the uptake of long-term injections for the secondary prevention of RHD and generally attributed non-adherence/non-compliance to a failure of Aboriginal families to provide care. This dominant focus on patient behaviour is "at the expense of focusing on features of the environmental, political, or economic systems that produce ill health and inequity" (Baum et al., 2009: 1969). Rather than identifying how the health system fails to provide accessible, acceptable, and/or effective services for Aboriginal clients, such research tends to lay the "blame for non-compliance on the Indigenous clients, establishing a cycle of suspicion" (Lowell et al., 2012: 204). Focusing on patient behaviour change is seductively easier than focusing on broad causes of disease states (Haynes et al., 2020), such as the ramifications of a history of colonial dispossession (Humphrey, 2006). Thus a biomedical approach can result in a blindness that rests responsibility with patients rather than seeing actions, such as self-discharging from hospital, as a form of 'micro-resistance' (Foucault, 1991) to hegemonic medical power (Humphrey et al., 2001; Saethre, 2009), or acknowledging that the enduring effects of colonisation may explain "beliefs or behaviors such as mistrust in medical advice" (Katzenellenbogen et al., 2013; Lowell et al., 2012: 206). In this way, 'the language of non-compliance is bound up with medical authority and control' (Haynes et al., 2020: 16) contributing to asymmetric power relationships between staff and patient, exacerbated by health care providers who represent another culture and political power (Mitchell et al., 2018). As preventing RHD involves at least ten years of painful monthly penicillin injections, Indigenous patients and their families are required to have a prolonged engagement with the health system.

Indigenous knowledges have only recently become a priority in RHD research (Haynes et al., 2020). Similarly, the potential of sociology, medical anthropology and community participatory action research approaches to effectively mitigate the impacts of colonisation through better integrating patient lived experience into the biomedical worldview has started to be recognised (Dudgeon et al., 2020). Such developments are both critical and urgent to interrogate and reveal the association between colonisation, racism, poverty and RHD. Failure to conduct research/interventions aimed at unravelling the mechanisms of poverty leaves "the root causes unchanged" (Coffey et al., 2018: 11). Further, attempts to treat RHD that do not meaningfully address inequities or acknowledge Aboriginal ways of knowing, being and doing (Martin and Mirraoopa, 2003) can result in 'collateral damage' such as "stigma, internalised blame, emotional suffering and hypervigilance that reproduces structural violence" (Anderson and Spray, 2020: 1).

1.3. Redistributing power dynamics: broadening the space of productive dialogue

Indigenous authors seeking to constructively address the impacts of colonisation have variously described the intersection between Aboriginal and Western worldviews with terms such as the cultural interface (Nakata et al., 2012), or liminal space, intercultural space, third space (Bhabha, 1994; Dudgeon and Fielder, 2006). Rather than being based in ‘the politics of polarity’, where one culture, knowledge system or discipline dominates another and shuts down inquiry or limits understanding, this intercultural space is conceived of as a space of productive dialogue (Zubrzycki et al., 2014). This space enables new positions and understandings to emerge by engaging in discussion and negotiation to explore new ideas and ways of working (Nakata, 2007). In addressing Aboriginal health needs, productive dialogue requires that all participants feel equally included, valued, and heard. We extend this concept to examine the intersection between Aboriginal and biomedical world views.

1.4. Decolonising the policy context

Efforts to create a more equitable, broader space for productive dialogue is observed in current shifts in RHD policy direction. The RHD Endgame Strategy seeks to influence and leverage off current Aboriginal health policy directions driven by the historic partnership between Australian governing and political bodies and Indigenous leaders and peak bodies “committed to addressing the structural and systemic changes that have led to the gap in outcomes, including life expectancy, between Indigenous Australians” (Pat Turner, CEO of the National Aboriginal Community Controlled Health Organisations, cited in Wyber et al., 2020: 10). New policy directions encompass new models of shared decision-making, the critical role of local, community-based knowledge, and the concept of Indigenous Data Sovereignty - a global movement outlining the rights of Indigenous peoples to govern the creation, collection, ownership and application of their data (Kukutai et al., 2020). Such decolonising policies offer a blueprint to broaden the space for productive dialogue between Aboriginal leaders, Community Controlled Health Services, policy makers, medical institutions, health practitioners and Aboriginal communities to identify/implement culturally responsive strategies and practices to transform existing biomedical/health structures and systems.

However, given that Indigenous healthcare delivery is located within a racialized social structure dominated by biomedical values (Durey, 2015), achieving the intended productive space will require a system-wide interrogation of power relationships in practice. This includes critical reflection and acknowledgement of power differences enacted at individual, professional, disciplinary and system levels (Walker et al., 2014). Such reflection is challenging, given that the intercultural space remains constrained by racism, dominant biomedical discourses and knowledge, and other forms of marginalization (Haynes et al., 2014). For example, superficially explaining substandard care with terms like ‘communication barriers’ and ‘lack of cultural competence’, distracts attention from understanding how power in post-colonial nations plays out in the health system (Durey, 2015; Humphrey, 2006). Critical analysis of the ways in which social inequalities are perpetuated by those with power and privilege (Durey and Thompson, 2012; Walker et al., 2014) is required to support system changes, including analysing the experiences and perceptions of RHD practitioners to understand institutional and interpersonal practices (Durey and Thompson, 2012; Hendrickx et al., 2020; Laird et al., 2020).

2. Methodology and methods

This study applies a Critical medical anthropology (CMA) lens. CMA emerged in the 1980s (Baer et al., 1986) as a critique of traditional medical anthropology’s tendency to take Western medicine

(biomedicine) at face value and act as a “cultural translator”, to increase adherence to recommended behaviors (Newnham et al., 2016: 2). CMA aims to make visible normalized/accepted power relationships, by applying a reflexive, critical stance to examine the links between individual perceptions and experiences and the broader social, political and economic context and dominant biomedical discourses and knowledge (Singer and Baer, 1995). We applied CMA to examine RHD practitioner perceptions, actions and agency and how these might reflect and be influenced by prevailing and dominant contextual factors, systems and structures (Panter-Brick and Eggerman, 2018; Witeska-Młynarczyk, 2015). Applying CMA enabled us to reveal the power dynamics and synergistic relationships between socioeconomic, historical, cultural factors, systems and structures (Long and Baer, 2018) that need to be addressed to better support Aboriginal people living with RHD (Haynes, 2021) and implement RHD Strategy recommendations (Wyber, 2020).

2.1. Participant selection

RHD practitioners were identified using purposive, snowball sampling to represent a variety of experiences relating to RHD and/or delivering projects, programs and services that focus on RHD (see Table 1). Geographical distribution was not part of the sampling criteria, however most participants had experience working within a range of health services in remote settings and larger centers across northern Australia where RHD is endemic.

2.2. Data collection

Interviews were conducted in May 2016 by the first author, a non-Indigenous (NI) social scientist experienced in qualitative methods, Aboriginal health research and program management. All interviews were conducted face-to-face in locations convenient to participants. With participants’ permission, interviews were digitally recorded, and transcribed. After providing informed consent, RHD practitioners described their involvement in RHD research or healthcare and responded to a series of open-ended prompts regarding their perspectives of factors impacting on the experiences of Aboriginal families living with RHD. Participants were asked their thoughts about gaps in knowledge, and appropriate approaches to address these gaps. More specific prompts were used if participants had not mentioned a pre-specified topic (see Appendix A). They were asked to consider the

Table 1
Characteristics of rheumatic heart disease (RHD) practitioners^a.

Role	Areas of employment	N ^b	Average years in an RHD or Aboriginal health related role
Health policy/ strategy or advocacy	Health policy and/or program development Publicly funded Advocacy and/or consumer representation	6	12
Clinical practice	Clinical practice in RHD health care (General practice; Cardiology; Aboriginal Community Controlled Health Services; Other primary care)	11	18
Research	Clinical and/or health services researchers Research program leaders Academic researchers Aboriginal researchers	14	15
Health service or program delivery	Health service delivery, coordination or management related to infectious diseases	3	28

^a Practitioners does not refer to clinical practice.

^b Some participants work in more than one category, therefore, the sum exceeds the total number of 22.

term ‘RHD’ as referring to the broad health context across the continuum from primordial prevention (housing, food security, economic equality) to acute care (hospital admissions for ARF or heart failure). The number of RHD practitioner interviews were limited due to the jurisdiction selected. Data saturation was considered achieved when no new information emerged in ongoing interviews.

2.3. Data analysis

Throughout the iterative data collection and analysis process we examined participants’ explicit meanings in their responses in the initial descriptive/semantic analysis phase; while deep engagement with the data and conceptual meaning making extended the quality of the data and findings in a second reflexive/interpretive phase (Braun and Clarke, 2019). The key themes and results arising from the integration of the primary (descriptive) and secondary (interpretive analysis) phases are depicted in Fig. 1 and discussed in detail in the results and discussion below.

Initial data analysis commenced during data collection using manual coding, allowing the researcher (1st author) to refine questions, to increase understandings of certain areas, and in some cases returning to earlier participants for further questioning. The analysis conducted during and after data collection resulted in broad descriptive categories. An interim analysis report was sent to participants for verification and further comments, and their replies incorporated. The initial categories were consolidated into descriptive themes by the 1st, 2nd and 3rd authors (all experienced qualitative researchers) who spent time collaboratively and iteratively re-ordering, recoding, and refining, until consensus was reached.

In line with our study aims this initial analysis gave us an understanding regarding *what* factors need to be accounted for in order to improve care. We then applied a CMA approach in our discussion of this analysis to identify how these factors both determine and sustain health inequities, as shown in Fig. 1 (above). This involved all co-authors working collaboratively and iteratively to critically apply their contextual and reflexive understanding of decolonizing theories, relations of power, health inequity and the influences of cultural, historical, political and economic factors on health care and health outcomes (Dudgeon and Walker, 2015; Walker et al., 2014). In this way we became cognizant of the contexts that influence and shape views, interactions, and events (Charmaz, 2017) allowing us to present a Discussion section that both interprets and contextualises – illuminating system factors using

participants’ experiences, and illuminating participants’ experiences using a knowledge of systems (Coddington, 2017).

2.4. Ethics approval

Ethics approval was obtained from the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC, 2016–2581), which includes an Indigenous sub-committee.

2.5. Establishing rigor - interrogation of positionality

Reflexivity is critical in establishing the rigor and trustworthiness of qualitative research (Boateng et al., 2019) and revealing how authors’ positions, assumptions and knowledge inform the research processes. The authors have extensive expertise in Aboriginal health service provision (social work, midwifery and nursing); qualitative, mixed and epidemiological research methods; and Aboriginal community-led action research. They used self-reflection, team discussions and research experiences to inform and question analytic assumptions and resolve differences in opinion (Hollway and Jefferson, 2013). An ongoing ‘courageous conversation’ (Singleton, 2014) informed how the authors framed the need for individual critical reflection/agency/responsibility about a system that has historically privileged both biomedical and non-Indigenous worldviews. Focusing on integrity and respect, the authors resisted blaming health professionals for the outcomes of system failings such as institutional racism. This conversation, undertaken in a spirit of productive dialogue recognised differences in our positioning, allowing the authors to reach, after many revisions (including following journal reviewer comments), the nuanced language used in this article. The four NI researchers acknowledge the critical input of the two senior Aboriginal authors in facilitating reflexivity and engagement in the courageous conversations around race and power that was integral to shaping some of our concepts and terminology. Finally, the trustworthiness of the analysis was further supported by sharing initial themes with interview participants (Morrow, 2005) and the analysis reflects the range and diversity of accounts.

3. Results

Twenty-two participants took part in face-to-face interviews, lasting between 30 and 180 min. Participants had between two and 35 years of

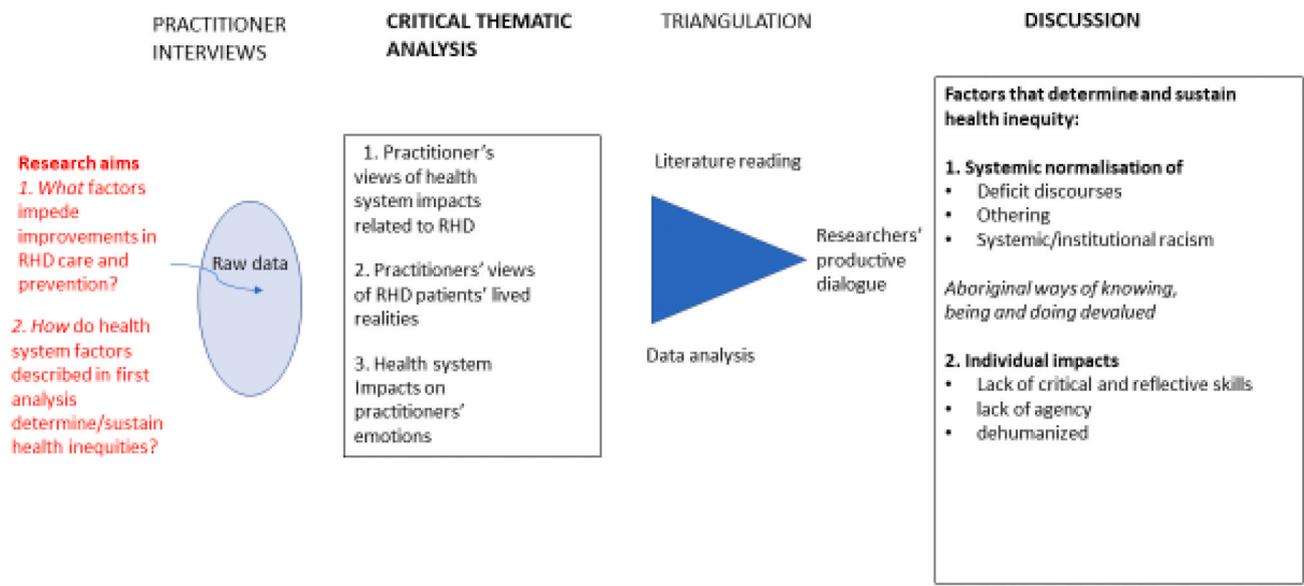


Fig. 1. Study structure.

experience in a broad range of roles either directly related to RHD or Aboriginal health (mean 18 years), nine having more than 20 years of experience. Many participants combined clinical and research roles. There were three Aboriginal participants and nineteen non-Aboriginal participants; five participants had personal experience of RHD through caring roles and family association. Many practitioners had spent long periods of patient care, working with, and often living in, Aboriginal communities, or conducting in-depth research. This enabled them to provide nuanced, reflective and informative first-hand observations about contextual factors of experienced RHD practitioners confirming a deep personal commitment in Aboriginal health. Practitioners were from both urban and remote NT locations. Some participants had been involved in qualitative research related to RHD lived experiences, including with adolescents, pregnant women, and children undergoing heart surgery. Several participants were key RHD policy advocates. Participants were coded sequentially to maintain their anonymity (P1, P2, P3). Type of RHD role, area of employment, and years of experience are summarized in Table 1.

Despite extensive efforts, only one Aboriginal Health Practitioner (AHP) was recruited to the study. AHPs in remote communities are often unavailable given their critical roles in community health settings.

The interviews generated extensive, rich data, reaffirming health system failures documented by other researchers (Brown et al., 2015; Howse and Dwyer, 2015), and consistent with findings from the qualitative RHD systematic review (Haynes et al., 2020). The RHD practitioners' perceptions and experiences of working with families and communities living with RHD are discussed in the three themes described below: 1. Health system impacts related to RHD; 2. RHD patients' lived realities; 3. Health system impacts on RHD practitioners' emotions.

3.1. Health system impacts related to RHD

Practitioners identified a range of complex and at times interrelated health system issues that impact on care for patients, families and communities. These issues encompass both pragmatic challenges such as staff shortages, technological challenges and poor communication as well as broader factors such as institutional racism.

3.1.1. Staff shortages

Several practitioners described staff shortages as a reason why families coming for regular injections were sometimes turned away or became impatient after long wait periods. This discouraged families from seeking services and increased their perceptions that health services were not doing the right thing. One practitioner commented that staff shortages resulted in limited time with patients as well as having "to practice in a way that is not culturally sensitive", for example due to limited staff they had been required to take large groups of medical students on hospital rounds which made patients feel uncomfortable or unsafe [P 17]. Some practitioners suggested overwork and having other patients with urgent needs might contribute to clinicians' reluctance to diagnose ARF where the probability appeared low or uncertain as doing so could generate extra work.

3.1.2. Lack of funding and lack of training/orientation

Practitioners suggested staff shortages were compounded by increasingly underfunded health services, poor recruitment practices and less accessible orientation and debriefing programs for health service workers and locums about the high risk of ARF and its long-term consequences. Consequently, one clinical RHD practitioner reported having "nightmares now thinking about the kids missed" as a result of normalizing the treatment of children presenting with sore knees, sore throats, and skin sores (all symptoms associated with ARF or its precursors) [P 2]. Several practitioners observed that staff recruitment is focused on clinical skills rather than cultural competence to work with Aboriginal people and communities in comprehensive primary care,

community development, health promotion and prevention roles.

Finally, the lack of AHPs, results in the employment of inexperienced, or poorly trained non-Aboriginal practitioners and service providers with limited communication and understanding of the complexities of Aboriginal communities where they work (Walker et al., 2014). In addition, many practitioners expressed disappointment that effective programs and practices had been discontinued because of the short-term nature of policy and funding cycles, as well as bureaucratic and technological changes.

3.1.3. Lack of communication and co-ordination

Several RHD practitioners expressed concerns about the lack of communication and coordination in transfers between hospitals and local clinics/health providers. They cited failures in providing accurate patient information in hospital discharge summaries and/or in patient referrals for treatment and follow-up care as negatively impacting Aboriginal health and wellbeing outcomes. As one RHD practitioner commented, some patients "may as well not have been in hospital at all", and that "lots of money has been spent to no effect" [P 1]. This failure was seen to exacerbate patients' fears about their health as well as inadequacies in care.

3.1.4. Limitations of technology

RHD practitioners observed that their increasing dependence on highly technical yet unreliable equipment often means more time solving equipment challenges than communicating with patients or colleagues. As one practitioner suggested, the reliance on systems using incompatible software for medical records means that communication between different services has become more difficult; observing that health care was often better in a workplace culture that recognised that "you can only do what you can" and was "more structured around the human than around the technology" [P 6].

3.1.5. Institutional racism

Some practitioners acknowledged the impacts of system bias in which the biomedical approach to health is seen as the "only right way ... you have to come with us [healthcare practitioners] or you'll be left behind" [P 12]. These practitioners observed how power differences are played out in institutional racism and are at the core of many system shortcomings. For example, one RHD practitioner concluded that the health system is "brutal toward Aboriginal people" asserting that "clumsiness, lack of coordination, inappropriate or poor care ... is institutionalized racism being played out" [P 3]. An extreme example of institutional racism was described by one RHD practitioner [P13] where "increasingly aggressive contact from the clinic about getting the [SP] shot" has resulted in clinicians reporting families to state services for child neglect because they have failed to bring their child in for the SP injection. For many Aboriginal families the fear produced by mandatory reporting is interlinked with the fear of having your children taken away. Similarly, another practitioner suggested that patient noncompliance (e.g. failure to follow medical instructions or discharging from hospital against advice) was likely a consequence of colonisation given generations of Aboriginal people have been "imposed upon and at certain times abused" [P 17]. Several practitioners believed that institutional racism results from poor understanding of Aboriginal ways of life, lack of recognition of Aboriginal culture and the failure of reconciliation.

Aboriginal people's sense of fatalism and/or reluctance to assert their needs, or seek legal recourse when they experience poor care (due to perceived and actual institutional racism) was also seen by some practitioners as a barrier to RHD treatment and prevention. According to one practitioner Aboriginal people have "normalized the way in which they are treated", not realizing "you shouldn't be treated like that, (you) don't know (that) you should desire a higher level of care" [P3].

3.1.6. Shame

RHD practitioners also observed that racism contributes to

Aboriginal people experiencing shame as a result of feeling judged, acting as a barrier to seeking health services when they have skin sores or scabies and/or are receiving injections. This can lead to a worsening of the condition that in turn may increase and compound shame. As one practitioner suggested, shame creates a fear of causing trouble among adults and children who have “*learnt to stop speaking up for themselves*” [P 7].

Conversely, some RHD practitioners described situations in which Aboriginal family and community knowledge or experience of RHD was ignored, and patients were turned away from clinics or given inappropriate treatment, such as paracetamol. In one case a child presented at a clinic with a sore throat, and was simply told to gargle and not further investigated or prescribed antibiotics. Subsequently the child developed ARF and required open heart surgery [P 10].

3.2. RHD patients' lived realities

RHD practitioners identified several factors that they perceived impacted on Aboriginal families living with RHD including poverty, household crowding and competing demands.

3.2.1. The role of poverty in RHD

Several RHD practitioners alluded to the dominant discourse of RHD as a ‘disease of poverty’ when discussing the impact of socio-economic factors on Aboriginal families, to enable good health outcomes. Practitioners reported that many Aboriginal families struggle to live week to week, and are unable to afford a refrigerator to store fresh food and medicines [P17], and some are further financially constrained through demands from extended family members to support drug misuse [P17]. Poverty added to the already challenging circumstances of needing to travel to distant cities for heart valve surgery. As one practitioner commented, for some families poverty was a more pressing problem than dealing with health issues. The issue is “*not [just] about RHD, they [Aboriginal families] don't have access to food - it is about abject poverty*” [P 18]. They highlighted that while RHD is a disease associated with social and economic disparity, most practitioners are uncomfortable talking about poverty and its structural causes, “*it's an ugly word*” allowing the “*dire*” disadvantage and complexity of Aboriginal people living in remote communities to become normalized, yet “*what is normal is not normal*” [P 18].

3.2.2. Household crowding

Practitioners frequently stated that household crowding was a key challenge for the prevention of streptococcal infections (precursor to ARF). RHD practitioners stated that housing needed to be a priority for RHD surgery patients, as often houses were not suitable for a child returning from open-heart surgery. As one practitioner noted, systemic shortcomings in housing provision in remote communities contributes to a sense of powerlessness to make improvements, stating that while “*we know housing is the problem, we don't know what to do next*” [P 1].

3.2.3. Healthy homes

The related subject of maintaining healthy homes revealed a discrepancy in the extent to which RHD practitioners felt that it was acceptable to advise people about household cleaning. As one Aboriginal RHD practitioner asserted, “*cleaning is not something you are born knowing*” [P 20], highlighting the need for information to be provided. While many RHD practitioners also saw a need for the provision of good information about the relationship between health and housing, they expressed uncertainty about an appropriate approach to address this need. As several practitioners suggested, this topic requires sensitivity as advice could be perceived as patronizing, shaming or bossy/dominating [P 14].

3.2.4. Competing demands for patients

Finally, RHD practitioners described their perceptions of the

differing and competing demands that patients experience that can complicate health care delivery. As one practitioner stated: “*people have to weigh up lots of priorities, [they] will choose other things over health, work, education – Western culture has a very different set of priorities*” [P 14]; and as another reflected “*Our rhetoric doesn't match their reality, we are not in their world view, they do not share our (researcher) interest in talking about RHD*” [P 18]. RHD practitioners' observations of this mismatch in social and cultural realities included instances where families with multiple equally important responsibilities (alongside caring for a child with ARF/RHD in hospital) may leave if required to stay too long, and are then perceived by hospital staff as being noncompliant. In another instance, citing the high reported rates of domestic violence, one RHD practitioner commented: “*no-one can look after their health properly if you're worried how you're going to live through the night*” [P 17].

3.3. Health system impacts on RHD practitioners' emotions

Many RHD practitioners had experiences that gave them insight into the complexities of providing services and programs. They expressed feelings of frustration, hopelessness, pessimism and sadness in not being able to solve ‘the problem’ of RHD.

3.3.1. Hopelessness

Several RHD practitioners expressed a sense of hopelessness in being able to make any real difference in Aboriginal health at either a personal practice or system level. Some believed that changes in health system policies had made it difficult to implement effective strategies to address RHD. One practitioner speculated that the reason the “*voice of those passionate [in advocating for change] about this are not being heard*” [P 11] may be due to the unrecognized prejudice and apathy associated with institutional racism. While one Aboriginal health practitioner stated that not speaking out could also be based on a fear that “*you will be labelled a radical, and it is difficult to be angry all the time and sometimes you need to pick your battles*” [P 3]. As one practitioner reflected, “*we know what to do, but it is getting harder [it is like] swimming against the tide ... the changes are like a tide turning*” [P 6].

3.3.2. Frustration

Practitioners' frustrations were profound regarding the communication failures described earlier, “*[it] seems hard to believe with all the communication technology we have, discharge information is not getting through*” [P 8]. Several RHD practitioners were frustrated with the lack of suitably competent staff, observing that nurses without training in management find it difficult to keep health programs on track when coupled with high staff turnover. Similarly poorly trained or inexperienced managers often don't understand or recognise the nature of the work clinicians do or the difficult conditions under which they do it, resulting in a loss of trust in those they report to, and who represent them at management levels.

3.3.3. Burnout

Finally, RHD practitioners talked about ‘burning out’ due to frustration, overwork and vicarious trauma, and being distressed at having potentially missed cases of ARF/RHD [P2]. Practitioners who felt overworked and tackling many demanding issues in addition to RHD, such as domestic violence or mental illness, believed that community expectations of service providers were too high, [P14]. RHD practitioners spoke about vicarious trauma when clinicians work in Aboriginal communities for lengthy periods suggesting that seeing the painful/stressful impact of injections for patients adversely affected clinicians' stress levels and ability to administer injections. The burnout associated with such trauma and frustration led to some practitioners changing their roles. As one practitioner stated “*I cannot work in communities anymore; it is too hard*” [P 12]. Practitioner's stress was often compounded by a perceived lack of support from management and/or the broader health system. As one practitioner observed, the interpersonal

relationships that could potentially diffuse burnout were lacking, they were particularly concerned that caring practitioners were becoming dehumanized “*it is the human element that makes it work ... a sense of humanity is needed to do this job, it’s more and more difficult to do this; put humanity first ...*” [P 6].

4. Discussion

This study advances knowledge of the impacts of a dominant biomedical discourse in the RHD space, reflecting health system failures, the complexities of Aboriginal lives, and practitioners’ personal challenges. The findings describing health system failures, poverty, racism, and poor communication resonate with other studies (Brown et al., 2015; Howse and Dwyer, 2015; Hendrickx et al., 2020; Laird et al., 2020) and reflect macro level forces that have individual disease impacts beyond RHD. The findings are also consistent with findings from the RHD systematic review (Haynes et al., 2020) and the Close the Gap Report 2020 (<https://ctgreport.niaa.gov.au/sites/default/files/pdf/closing-the-gap-report-2020.pdf>). However, there are few findings regarding emotional responses such as frustration, distress and hopelessness in health system research in cross-cultural contexts (Wilson et al., 2016; Heyhoe et al., 2016).

Applying a CMA lens to provide insight regarding the mechanisms by which the dominant biomedical worldview both sustains health inequity and impedes positive, systemic transformation reveals a gap/contradiction in participants’ discourse and practice. On the one hand participants’ generally had a good capacity to identify concepts such as racism, need for cultural awareness/competence, the influences of biomedical dominance and power differences. On the other hand most practitioners externalized the system issues and only a few were reflexive about the role of colonisation, and the disempowering effects of generations of oppression and trauma upon Aboriginal people’s health beliefs and practices. Overall there was a lack of critical reflection among most practitioners regarding how their understandings, beliefs and actions might contribute to sustaining or transforming the existing structural inequities in the health system (Walker et al., 2014).

Thus, practitioners tend to describe systemic failures from an ‘insider’ perspective, often blaming the system and patients with little critical reflection on their own agency. This lack of reflexivity leaves much unspoken, such as the ongoing effects of colonisation and trans-generational trauma and alternative approaches to addressing Aboriginal needs and priorities. We therefore include our observations about the ‘unsaid’ alongside the ‘said’ in the discussion below to reveal the mechanisms by which the dominant biomedical worldview systemically determines and sustains health inequities. Firstly, we identify from practitioners’ interviews examples of the dominant discourses and related worldviews (cultural and social beliefs) that result from and maintain the biomedical status quo. Secondly, we discuss the impact of biomedicine on practitioners’ perceived lack of agency and emotional responses to health system deficits. Finally, we suggest how a deeper understanding of the impacts of a dominant biomedical worldview can inform the direction of system, organization and practitioner change that is needed.

4.1. Interrogating the mechanisms of a biomedical worldview in RHD discourses

The interviews reveal discourses reflecting the impact of a dominant biomedical worldview including deficit discourses (Dudgeon and Walker, 2015; Fogarty et al., 2018); Othering (Thompson & Kumar, 2011); and institutional racism. Participants’ language often reflects a broader socio-cultural tendency to problematize Aboriginal people’s beliefs, behaviours and life choices. For example, describing RHD as a “disease of poverty” obfuscates the complexity of the issues involved. Doing so suggests poverty is the intractable fault of Indigenous individuals/communities rather than the result of ongoing colonisation,

structural and systemic factors (Wain et al., 2016). One practitioner observed a general reluctance/inability on the part of some health practitioners to acknowledge structural inequities, or to talk more deeply about poverty and its structural causes [P 18]. Such reluctance together with a deficit discourse meant that the “dire” disadvantage and complexity of Indigenous peoples in remote communities becomes normalized (Fogarty et al., 2018) and system failures become further entrenched. The notion of “overcrowding” can reflect a failure to recognise that ‘close living’ might be a carefully considered positive choice grounded in cultural obligations and expectations, rather than a behaviour needing change. The term also obscures failures of the system to provide affordable housing appropriate to Indigenous needs, values and ways of being (Greenop and Memmott, 2016). Focusing on deficits draws attention from strength-based solutions for reducing RHD and reinforces a dominant narrative that white people/outsideers have the solutions to Aboriginal problems (Kowal, 2015) and fails to recognise the importance of Aboriginal voice in determining effective and sustainable solutions.

Deficit discourses also contribute to the ‘Othering’ of Aboriginal patients as different and devaluing alternative culturally embedded ways of knowing, being and doing (Bessarab, 2015; Martin and Mirra-boopa, 2003). Othering such as this reveals embedded assumptions of families living with RHD not being interested, maintaining a separateness that bypasses engaging with and relating to families to find out how best to convey information (Haynes et al., 2019). As deficit discourses are normalized with biomedical power/knowledge and dominant cultural values, they effectively limit thinking outside the biomedical paradigm (Ivers et al., 2014) narrowing the space for productive dialogue. Normalizing an association between Indigeneity, marginalization and poor health has become inextricably linked in biomedical narratives, controlling the social discourse, and reinforcing conditions (such as poverty and disadvantage) that cause disease. RHD practitioners identified that some Aboriginal people had normalized being treated in a racist way, resulting in a degree of fatalism, or acceptance of being treated poorly and negatively stereotyped.

Normalizing deficit discourses based on race or ethnicity, can become embedded as institutional racism, the effects of which further negatively impact wellbeing (Durey et al., 2012; Macedo et al., 2019). Institutionalized racism has been identified as a cause of continuing health disparities in countries where Indigenous people have been colonized (Bourke et al., 2019; Ivers et al., 2014). Practitioners’ discourses identified the inherent institutional racism within the health system underpinning a range of inequities in Aboriginal healthcare.

4.2. Impact of a biomedical worldview on RHD practitioners’ emotions and sense of agency

RHD practitioner reports of working at the intersection of complex Aboriginal health problems and health system limitations revealed a myriad of challenges, including feelings of frustration, hopelessness, sadness, pessimism, powerlessness at being unable to make a difference, due to/resulting in a lack of improvements in RHD.

Dissonance between a clinician’s identity as a caring human and dehumanizing system constraints can be traumatic, as evidenced by the practitioner having “nightmares now thinking about the kids missed” [P 2]. The significance of the dehumanization in clinicians’ experiences of working within a system siloed in biomedicine inhibits the realization of their positive attributes as clinicians. Moreover, the increase in bureaucratic reporting requirements, and technological ‘advances’ to enhance communications, often delivered the opposite – creating a general weakening of inter-sectorial communication and loss of professional networks to support each other.

It is not surprising, given the scale of these challenges, to find that RHD practitioners were often unable to drive/promote alternative ways of working, by incorporating Aboriginal perspectives and conceptions of health to improve their experiences in the health system. Health

practitioners are caught in a double bind, with an eroded sense of agency to effect health systems change, often constrained by an entrenched deficit discourse regarding the capacity of Indigenous people to enact their own sense of agency.

Although practitioners' identified problems that they perceived were their responsibility to solve (Kowal, 2015), they also felt a level of despair and hopelessness that external forces were beyond their control. Their resultant frustrations were often combined with descriptions of feeling powerless or unable to make a difference despite knowing what needs to happen, and seeing no real changes occurring. Their enculturation within and commitment to the biomedical paradigm rarely gave health practitioners an opportunity to develop the critical sociological analytical skills essential for seeing and advocating for alternative worldviews. Given the "sets of beliefs and assumptions that express how cultures interpret and explain their experience" (Tilburt, 2010: 178) it is essential that health practitioners have the opportunity to acknowledge and understand different worldviews in cross cultural contexts in order to both address health disparities within the system and to "transform the culture of health care professionals toward a more self-reflective, humble, and open-minded posture" (Tilburt, 2010: 178).

Despite being "knowledgeable, highly competent, and caring", the existing personal and external constraints described by RHD practitioners in this study mean they often "contribute to a system which does not always operate most effectively for the patients for whom it is supposedly designed" (Collyer et al., 2017: 97). RHD practitioners' capacity to collaborate meaningfully across disciplines is challenged by the lack of training in management, cultural safety, reflexivity and trauma-informed care, combined with lack of institutional support, workforce shortages and funding for primordial prevention, health literacy and advocacy. Workforce shortages increased work pressure and stress for those remaining onsite; contributing to a decline in trust and communication breakdown between clinicians, resulting in gaps in service provision. This is particularly challenging for much-needed primary health programs, which require time and consistency. Similarly, lack of orientation or cultural immersion programs for working in Aboriginal communities means practitioners may be culturally ignorant and under-prepared to work in the intercultural space where the treatment and management of RHD and other diseases is impacted/complicated by a complex and intractable array of social and cultural determinants, especially in remote locations.

4.3. Recommendations - generating a productive dialogue regarding RHD policy and practice

The above findings, and contemporary critical literature, provide an alternate, critical discourse and theoretical paradigm to inform recommendations to transform public health policy and practice related both to RHD and Aboriginal health more broadly.

Productive dialogue, where all participants feel equally included, valued and heard, and where differences are identified, respected and maintained (Ngurruwutthun, 1991) and negotiated (Nakata 2012) is critical to inform the direction of system, organizational and practitioner transformation (Walker et al., 2014) to implement strategies as outlined in the RHD Endgame report. Recognising the lack of space for productive dialogue between biomedical 'technical' responses and the social nature of RHD (Haynes et al., 2020) proposed that Aboriginal strengths, knowledges and worldviews provide guidance for the ways forward. For example, Aboriginal social practices related to empathy/emotional care and collective relationships, Indigenous strengths (history, language, culture, knowledge) specific to local realities and social contexts provide important alternatives to individualized biomedical approaches (Haynes, 2021). More broadly, there are existing policy frameworks and plans, including the *National Aboriginal and Torres Strait Islander Health Plan 2013–2023*, that emphasize the centrality of culture and Indigenous rights to safe, healthy and empowered lives (Commonwealth of Australia, 2013). The health policy vision, principles and priorities

provide a platform for change if the strategies are adequately funded and resourced. It requires that "individuals and communities actively engage in decision making and control", "supported by housing, education, employment and other programs focused on eliminating the causes of health inequality" (Commonwealth of Australia, 2013: 7).

Recommendations to address health system failures in the RHD policy space include actions to support Aboriginal self-determination in the Endgame Strategy (Wyber et al., 2020) (see also <https://youtu.be/AkgDwmSz-EA>), specifically: funding communities to develop Indigenous-led culturally responsive programs, increased and sustained resourcing of an Aboriginal-led strategy implementation unit, Aboriginal health services and peer support programs, and ensuring culturally safe health provision (Wyber et al., 2020). Similarly, recent epidemiological research has recommended Aboriginal leadership for the governance, reporting and dissemination of RHD data to support innovative local solutions (Katzenellenbogen et al., 2020). Even when funded, policy and practice changes are often difficult to achieve, as implementing actions to facilitate Aboriginal self-determination requires new ways of working based on shifting power dynamics within the health system.

Broadening the space for productive dialogue addresses challenges identified in the RHD practitioner interviews, and the recommendations of the Endgame report. That is, while practitioners described systemic failures from an 'insider' perspective, their insights were constrained by their location within the biomedical paradigm and the social structures (beliefs and values) within the organisations in which they work, structures that they (intentionally or not) may have helped to reproduce (Lea, 2012). This limits practitioners' capacity for insight regarding their own agency, role and capacity to make a difference; or to acknowledge how the historical and structural determinants of disparities might act to maintain their position of privilege; or enhance their ability to imagine or actively support and advocate for alternatives outside of the biomedical structures.

Most of the research team have been engaged in Aboriginal community-based projects that provide evidence of the effectiveness of applying decolonizing principles to broaden the space for productive dialogue. These projects offer alternatives to 'biomedicine-only' approaches to health through collaboration with both Aboriginal people/communities and other disciplines (Haynes et al., 2019; Mitchell et al., 2021; Bessarab, 2015; Dudgeon et al., 2020; Laird et al., 2020; Marriott et al., 2020). This evidence reconfigured the RHD landscape and informed sections of the Endgame recommendations as well as the 2020 Australian RHD Clinical Guidelines (RHD Australia (ARF/RHD writing group), 2020). We draw on these learnings to suggest three mechanisms for implementing recommendations: 1). Small-scale, strength-based, community-led local changes; 2). Community-led research focused on action that uses critical, decolonizing social science approaches; and 3). Cultural safety training including reflexivity regarding power dynamics.

4.3.1. Small-scale, strength and place-based, community-led local changes

Approaches that create a productive dialogue between medical knowledge and local Indigenous knowledges, community priorities and other disciplinary expertise besides biomedicine can be implemented through community development, primary health, prevention, and community-led both-way health education utilizing APAR (Dudgeon et al., 2020). This approach values Aboriginal knowledge systems and the reciprocal co-creation of knowledge, which the collective researcher group termed 'both-way learning' (Herbert, 2000) also referred to elsewhere as 'two-way learning' (Marriott et al., 2020). Such work is likely to result in incremental, small-scale, positive, strength-based actions that improve and counter feelings of powerlessness and hopelessness among health practitioners, communities and people living with chronic diseases (Haynes et al., 2019; Laird et al., 2020).

In this context, practitioners are skilled in partnering with and enabling local Indigenous peoples to give expression to their own vision, skills and community processes, rather than focusing on changing their

values, attitudes or behaviour (Ingamells and Johnson, 2018). In addition, practitioners work collaboratively in multi-disciplinary teams experienced in primary health, health prevention, education and promotion, often including people who can act as 'knowledge brokers', 'change agents' or 'go-betweens' (Haynes et al., 2016; Ingamells and Johnson, 2018). This is particularly important where barriers to change operate at policy, management and practitioner levels. Change agents are therefore indispensable to facilitate power shifts with a broad variety of stakeholders.

4.3.2. Research that applies critical, decolonizing, strengths-based approaches

To both support the approach described above and to provide accountability to funders, there is a need for developmental evaluation approaches that facilitate change, community partnering and evidence of what works. It is critical that Aboriginal researchers and communities are central in evaluations to ensure their contexts and cultural perspectives are privileged.

Empowerment through ownership of the research process is a primary requirement in enabling communities to find locally appropriate place-based solutions for preventing health conditions associated with social and economic disparity. Recent projects have included evaluation components that demonstrate the factors that support community empowerment and effective partnerships in health research concepts (Haynes et al., 2019; Bainbridge et al., 2019; Dudgeon et al., 2020; Ingamells and Johnson, 2018; Oetzel et al., 2018). Specifically, these highlight the need for: both-way (two-way) learning; community voices to be heard (co-design in setting the research agenda); critical thinking to be fostered; recognition of local contexts; and for shifts in power relations as a result of the process undertaken (Haynes et al., 2019; Dudgeon et al., 2020; Ingamells and Johnson, 2018). Such approaches have been promoted in many global Indigenous contexts, including Canada (Maar et al., 2011) New Zealand (Smith, 1999), Southern Africa (Keikelame and Swartz, 2019), and Brazil (Teixeira and Silva, 2015). Importantly these research findings highlight the opportunities to transform intercultural understanding, clinical practice and policy. Similarly, better understanding of the lived experience of RHD will also contribute to broadening the space for productive dialogue to improve RHD diagnosis, treatment and ongoing management (Haynes, 2021).

4.3.3. Cultural safety including reflexivity regarding power dynamics

Productive, transformative, action-oriented dialogue can only occur when everyone in the space acknowledges the unequal power relations not only between dominant and minority populations but also within and between service delivery, policy sectors and professions/disciplines. This means examining the power and privilege "that we are afforded because of our different group memberships, including our professions" as well as our social and cultural identities (Walker et al., 2014: 205). It also means recognising the mechanisms that link power and privilege to the perpetuation of disadvantage and marginalization.

This work involves the skill of critical reflexivity as it is deceptively easy to be culturally blinded to the effects of white privilege, normalized deficit discourses and institutional racism. And as critical reflexivity often demands letting go of certainties and familiar practices other skills required include the ability to work outside one's own comfort zone and to work collaboratively with different knowledges and expertise (Walker et al., 2014). Finally, the discomfort, guilt or defensiveness that reflexivity can create should be recognised as a positive indicator of power shifts and the broadening space for dialogue (Walker et al., 2014).

Supporting and bringing people along on the journey without alienating them, requires skillful facilitators and mentors (Singleton, 2014). Rather than 'cultural awareness' type training an ongoing focus on cultural safety prioritises a commitment to social justice and a critical inquiry focus on power imbalances and inequitable relationships in health care at both the individual and institutional levels (Browne et al., 2009). Cultural safety broadens the space for productive dialogue by

beginning with "an explicit focus on social and organizational structures and inequities, interrupting the discourses that sustain marginalizing structures and practices, and individual agency as positioned within those structures and discourses" (Browne et al., 2009: 175).

Encouragingly, the results of workshops that apply cultural safety concepts and tools confirm that the understanding and competence developed through critical reflection allowed practitioners to identify their areas of ambivalence. And, over time, reach a level of proficiency in identifying strategies to change and/or reinterpret institutional and social policies, practices and processes that impact negatively on Indigenous people (Kowal and Paradies, 2005).

5. Conclusion

Our conclusions resonate with a growing body of work by internationally recognised critical medical anthropologists such as Napier et al. (2014) who argue that if biomedicine continues to focus only on evidence-based practice, expectations of adherence, hierarchies of treatment, and disease etiology, then "multiple barriers will go unrecognized including ... cultural and language differences, distrust of medical systems, past negative experiences and stigma" (Napier et al., 2014, p. 48). Individuals are often constrained by the beliefs and values in the organisations in which they work, structures that they in turn help to reproduce (Lea, 2012). Practice and research that counters reductionist approaches by being "sensitive to culture, context and diversity" is critical (Bainbridge et al., 2019: 2). Our recommendations require an investment of time, resources and openness to "new mindsets, new sensibilities, new forms of relationship and new skills, at every level ... [as] the mutual convergence of biological and social sciences creates new opportunities" (Napier et al., 2014: 48). Work towards achieving productive dialogue in the intercultural space is required to 'change the conversation' around experiences of health, illness and wellbeing for Aboriginal individuals, families, and communities living with RHD and other acute and chronic diseases. The broader health system can learn much by applying an Aboriginal lens when considering the notions of health, social and emotional wellbeing, illness and the body. By doing so, positive and successful approaches can be identified whereby strong communities are formed, a sense of agency to address inequity is afforded to practitioners working within the health system, and the health and wellbeing of Aboriginal people are advanced (Neumayer, 2013).

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Author contributions

Emma Haynes: Initial Conceptualization, Methodology, Data curation, Writing – original draft. Roz Walker: Conceptual, writing, editing and article preparation. Alice G. Mitchell: Conceptual, writing editing, and article preparation. Judy Katzenellenbogen: Conceptual, diagram, writing and editing. Heather D'Antoine: Conceptual, writing and editing. Dawn Bessarab: Conceptual, writing and editing.

Declaration of competing interest

The authors declare there is no conflict of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.socscimed.2021.113829>.

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