Acute rheumatic fever and rheumatic heart disease: an insight into Aboriginal health disadvantage and remote Australia

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Australian Aboriginal people have the highest rates of these diseases in the world

his issue of the Journal provides a range of insights into acute rheumatic fever (ARF) and rheumatic heart disease (RHD), highlighting the divergent perspectives of health providers, health care services, researchers and those afflicted with poor health. From the exposé of the realities of biomedical research in remote Aboriginal communities by McDonald and colleagues (page 511), ¹ through discussions with patients and families by Harrington et al (page 514), ² and finally a study of the association of ARF/RHD with B-cell antigens by Harrington et al (page 507), ³ clinical and biochemical aspects of ARF/RHD are explored. We also gain insights into the realities of usually urban, non-Aboriginal researchers working in remote Aboriginal communities; the intercultural gap between urban and remote, and Aboriginal and non-Aboriginal concepts of disease, health and health care.

Successive generations of medical students trained in southern Australian hospitals will have seen the advancing age of the cohort of patients with "interesting and educational" murmurs attributable to RHD, to the extent that it is now rare to come across a non-Indigenous Australian with RHD. ARF/RHD is an eradicable condition, rates of which have declined dramatically in industrialised countries where social and economic disadvantage has decreased. ⁴ Importantly, this is not a condition to which Aboriginal people are innately susceptible — in the past, RHD affected all Australians. However, although Australia is among the world's wealthiest nations, Australian Aboriginal people today hold the dubious distinction of having the world's highest rates of ARF/RHD. ⁵

In the study by Harrington et al of prophylaxis for ARF, participants describe the broad range of impediments to accessing regular penicillin prophylaxis, highlighting the importance of venturing beyond the new mantra of chronic disease "self-management" and individual autonomy to understand the reasons behind "the problem of noncompliance". An empiric response to non-compliance with ARF prophylaxis is to refer to an individual patient's autonomy, assuming that failure to attend is a conscious decision based on avoiding the pain of injections. The beliefs and attitudes of those surveyed contradict this premise, raising questions about the concepts of autonomy and paternalism as they relate to Aboriginal health.

Cass and colleagues have previously described how communication between Aboriginal Australians and a largely non-Aboriginal health workforce can result in frequent and often unrecognised miscommunication. Along with the experience of McDonald et al of what was viewed by some research participants as the unsympathetic behaviour of researchers seeking written consent, this challenges all non-Aboriginal Australians involved in health care to respect and reflect the wishes and beliefs of Aboriginal people in both health care and health-related research. Active participation of Aboriginal people is imperative at all levels of health research and health care delivery involving Aboriginal people. Further, as was borne out in the National Aboriginal Community Controlled Health Organisation chronic ear infection trial, Aboriginal control of health care and health research is both attainable and effective.

The two articles by Harrington and her colleagues further exemplify barriers residents of remote Australia may face in accessing primary health care services.^{2,3} The vast majority of staff in the community health service described were female and, despite nothing to suggest a substantial female susceptibility to ARF/RHD, only 7% of those surveyed were male.² Unfortunately, without the views of a significant sample of men, it is not possible to extrapolate these findings beyond women. Aboriginal men bear a disproportionate level of health disadvantage, and impediments they face in accessing health care are a cause of concern and a focus for action.⁸

The insightful studies seen in this issue of the Journal underscore the importance of recognising, as a minimum standard, the active participation of Aboriginal people through all phases of health research and health service provision involving Aboriginal individuals and communities. Only by doing so will we recognise, celebrate and bridge the intercultural divide as it relates to a chronic disease such as RHD. While the underlying socio-economic determinants of ARF/RHD may be clear, the solutions are neither simple, nor exclusively in the domain of health services and health resources. Primary prevention of ARF/RHD requires broad-scale political commitment to addressing the social, economic and environmental inequities experienced by Aboriginal Australians. In the meantime, there is great capacity for health care providers to concentrate on meeting the needs of those with ARF/RHD through better diagnosis, prevention and access to care.

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