

A systematic review of the lived-experiences of rheumatic heart disease of Aboriginal and Torres Strait Islanders in Australia

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BACKGROUND

For Indigenous Australians, life and health exist in a context of post-colonialism and its aftermath of dispossession, marginalisation, poverty and powerlessness. Their worldview differs vastly from that of health service providers and from the biomedical model of care

Understanding this context, and the experiences of people living with **rheumatic heart disease (RHD)** can inform appropriate and effective interventions for disease prevention, treatment and management – ultimately leading to improved health outcomes

Qualitative inquiry allows exploration of the experiences of people living with RHD as well as how people live through and respond to those experiences as they navigate their journey through the health system

This study aims to examine existing peer-reviewed literature to summarise the knowledge gained from qualitative enquiry of the experiences of people living with RHD. The study evaluates the need for the exploration of the lived experience of Indigenous Australians living with RHD



METHOD

Approach: This is a configurative review which aims to interpret and arrange (configure) information to develop concepts. The approach is exploratory and, although the basic methodology is determined in advance, specific methods are adapted and selected (iteratively) as the research proceeds

Databases: Web of Science; PsychInfo; CINAHL; SCOPUS and AustHealth (Informit); Google Scholar; additional citation searches of all relevant publications

Population: Participants who utilise/provide RHD healthcare within in Australia

Qualitative meta-analysis: will be the next step of the review, this is a distinctive kind of research integration study in which the findings from completed qualitative studies in a target area are combined

Search: a 122 term search was applied – a combination of key words and medical subject headings (MESH) for rheumatic heart disease, rheumatic fever & qualitative research, plus terms relating to the concepts: socio-cultural context; Health behaviour /decision-making; knowledge/ attitude/ belief/ understanding

RESULTS

[n=2] published empirical RHD research studies utilising qualitative inquiry...*

Author, date	Location	Method	Participants /sample	Objective and main findings
Mincham et al (2003)	Remote, Western Australia (Kimberley)	In-depth, semi-structured interviews	Patients with ARF or RHD or parents (7)	<i>To describe, from a patient perspective, factors leading to suboptimal management of individuals with RF and RHD</i> > Variable levels of understanding of ARF/RHD > Compliance linked to positive patient-staff interactions > Participants desire more accessible and culturally appropriate information about RHD > Negative effects of living in remote location
Harrington et al (2006)	Remote, Northern Territory (North East Arnhem Land)	Semi-structured informal interviews	Patients (15), relatives (18); Aboriginal health workers (9); health service providers (9)	<i>To identify factors that affect ARF prophylaxis for remote-living Aboriginal patients, and to determine the proportion who received adequate prophylaxis</i> > Providing nurturing, holistic care, creating a sense of belonging generated trust & treatment compliance > Differing expectations between patients and health service providers regarding responsibility for care > Biomedical understanding of ARF/RHD and sense of responsibility for own health related to adherence

* ...HOWEVER

Iterative development of inclusion/exclusion criteria at the eligibility stage identified the importance of expanding the criteria to include:

Non-empirical RHD studies; provides insight into patient/ community/ contextual perspective	Empirical RHD study has non-qualitative primary objective but engages qualitative methods	Empirical study has primary qualitative objectives <i>not for</i> RHD related outcomes	Empirical study with marginal RHD content
N = 4	N = 3	N = 1	N = 1

- These articles contribute contextual factors surrounding RHD, thus contribute to an understanding of the lived experience of RHD
- All full text articles will be included in a qualitative meta-analysis

EXPANDING THE SEARCH

- An additional pilot search identified 58 non-RHD Aboriginal lived experience papers, including 25 general chronic and 3 heart disease related studies
- This indicates more qualitative research exploring lived experience is being done outside of RHD and we can potentially learn from their findings and lessons
- A recognised study limitation is the inclusion of only peer-reviewed research
- A more extensive search that includes grey literature is necessary, particularly in the context of Aboriginal health in Australia

CONCLUSION

There is need for qualitative inquiry to explore lived-experience of RHD in Australia

WHERE TO FROM HERE:

- A qualitative scoping study involving interviews with key informants is underway to further explore what is known about the lived experience of RHD in Australia
- Results from this review and scoping study will inform a PhD study funded by the END RHD CRE that will explore lived experience of RHD (PhD scholar Emma Haynes)
- A meta analysis of all global RHD and qualitative studies will be performed contributing to an understanding of the lived experience of RHD globally. A preliminary review indicates a similar paucity of qualitative inquiry in RHD on a global level

