

WORLD CONGRESS ON RHEUMATIC HEART DISEASE

2-4 November 2023 • Abu Dhabi



Submission Id: 98

Title: RHEUMATIC HEART DISEASE PATIENT VOICES FROM THE PACIFIC: A MIXED METHODS STUDY FROM FIJI

Authors: Jyotishna Mani, Eric Rafai, Stephen Howie, Christopher Bullen, Bridget Kool, Braden Te Ao, Cameron Grant, Andrew Steer, Donald Wilson, Philip Hill, Devina Gaundan, Devina Gaundan, Sera Witherow, Jokaveti Momo, Roneel Chandra, Maria Mow, Bert van der Werf, Sue McAllister

Background & Aims: Rheumatic Heart Disease (RHD) and Acute Rheumatic Fever (ARF) remain highly prevalent in Oceania. The risk of death amongst people living with RHD in Fiji is eight times higher than for the general Fijian population. Diagnosis is frequently delayed. Symptoms can be subtle, only becoming apparent at critical life events, for example during childbirth. Health service access is one of the major determinants of health in the causal pathway from Group A Streptococcal (GAS) exposure to ARF to RHD death. This study describes preliminary findings of patient voices and experiences in accessing health services for ARF and RHD.

Methods: A mixed-methods study aiming to recruit 250 people with newly diagnosed ARF or RHD is being conducted. Cases are being identified from school, community outreach, and antenatal echo-screening, and from hospital admissions in the Central and Northern Divisions. A questionnaire was developed and pretested and captures demographic and health-related characteristics of participants, and patient experiences. The World Health Organization "Tool to estimate patient cost" was used and modified for patients with ARF and RHD and to ensure relevance to the Fijian context. The questionnaire was administered by trained research officers either via phone or face-to-face interviews. Data was entered into REDCap software. Quantitative data was analysed using R Software and qualitative data was coded and analysed using NVIVO software.

Results: To date 186 people have been enrolled, of whom 152 (82%) are i-Taukei (indigenous Melanesian Fijian) and 22 (12%) are of Fijian Indian descent. Most (n=153, 82%) are female. Of those enrolled 70% were patients and 30% were parents/guardians. Virtually all cases (99%) had RHD (rather than ARF). RHD cases severity was classified as mild (66%); moderate (20%); severe (12%); or uncertain (2%). Most participants (n=176, 95%) experienced RHD symptoms. The most common symptoms were shortness of breath, feeling tired and general weakness, and chest pain. More than half (52%) did not seek treatment or advice. Among those seeking care from a formal healthcare provider, the main reasons included severe symptoms and free and affordable healthcare. Participant stories of living with disease included having family members with RHD or having lost family members to RHD; classroom bullying; daytime somnolence caused by ARF; lack of family understanding of the disability caused by RHD; stigma and depression; and sexual reproductive concerns. Concerns expressed relating to the accessibility of care included late presentations due to financial and geographical barriers to healthcare; poor mental health in those living with RHD; the need for health education/counselling/peer support for those with RHD and/or ARF and their families; the need for sexual reproductive health education/peer support; physical health crises during childbirth and disabilities experienced by people living with RHD.

Conclusions: Rheumatic heart disease is a chronic debilitating illness affecting people at a relatively young age. Both RHD and ARF cause a broad spectrum of physical and mental health issues which are frequently poorly understood and misinterpreted. Descriptions of patients' voices and patient experiences provide insights into potential strategies to improve their health and contribute towards the design of health interventions to provide better support to people with RHD.