

Whānau experiences of Acute Rheumatic Fever and Rheumatic Heart Disease in Aotearoa, New Zealand

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Rates of acute rheumatic fever (ARF) and its sequela, rheumatic heart disease (RHD), are decreasing in most developed countries. In Aotearoa however, ARF remains a significant health problem whereby ethnic, social and demographic inequities persist. Māori and Pacifica children have the highest ARF rates nationally.

This presentation is based on two qualitative kaupapa Māori studies that undertook ethnographic observations and/or qualitative interviews with 113 Māori and Pacifica participants and 33 health care providers from seven District Health Board areas. The studies explored whānau experiences of ARF/RHD, including pathways to and through diagnosis and treatment to inform recommendations for service provision and policies.

Four key themes were identified from these studies: 1) ARF/RHD stressors; 2) Health service model of delivery; 3) Interpersonal approaches to health care; 4) Adolescent care. ARF/RHD affected financial status, employment and education of whānau resulting in significant emotional, social, and economic stressors. Commonly, ARF/RHD services were not flexible enough to reduce access barriers or to manage the challenging contexts in which Māori and Pasifika lived, in timely, effective or meaningful ways. Whānau reported receiving 'rough treatment' and experiencing racist encounters while in hospital. Young patients described how challenging they found coping with RF treatment and health professionals reported insufficient training or access to resources to respond to adolescent needs.

These findings suggest that ARF/RHD services need to employ integrated support models promoting culturally safe and responsive, youth and whānau centered approaches.