

## **“That heart sickness”: Aboriginal adolescents’ experiences of RHD and open-heart surgery**

### **Introduction:**

The burden of rheumatic fever is almost entirely borne by young Aboriginal people in northern and remote locations in Australia while it has been nearly eradicated in other parts of the nation. Ethnographic studies provide understanding about how the disease and health care dynamics are perceived by those affected by the condition. Such studies are useful to inform nuanced care, prevention and advocacy strategies.

### **Methods:**

An ethnographic study, using participant observation and serial interviewing, was undertaken in the Northern Territory between 2013 and 2016 focusing on adolescents with ARF and RHD, and their families, particularly around the requirement for long-term management. In four study sites, the subject of adolescence was explored, with a focus on social, environmental and domestic boundaries. Four young Aboriginal females with experiences of cardiac surgery for RHD were collated as case studies.

### **Results:**

Adolescents are ‘held’ within a loosely bounded domain with certain key relationships, such as grandmother, being central to their wellbeing. Structural violence, the unintentional and indirect harm caused to patients due to healthcare structures, emerged as a strong theme in the case studies.

### **Conclusion:**

Healthcare services for young Aboriginal people with RHD, including those experiencing cardiac surgery, can be much improved with increased understanding of adolescents’ life-worlds, as well as how the services themselves impact young people.