

P29

Using Research: Educational Resources for Rheumatic Heart Disease in Women

Geraldine Vaughan^{1,*}, Suzanne Belton^{5,2},
Sophie La Vincente^{4,7}, Linda Bootle³,
Elizabeth Sullivan^{2,6}

¹ *University of Technology Sydney, Australian Centre for Public and Population Health Research (ACPPHR), Ultimo, Australia*

² *Menzies School of Health Research, Darwin, Australia*

³ *Aboriginal Maternal Infant Health Service (AMHIS), Western NSW Local Health District, Australia*

⁴ *Reach, Switzerland*

⁵ *Northern Territory Primary Health Network, Darwin, Australia*

⁶ *University of Newcastle, Faculty of Health and Medicine, Newcastle, Australia*

⁷ *Telethon Kids Institute, Nedlands, Australia*

Background: A study of Aboriginal women's journeys with Rheumatic Heart Disease (RHD) in Australia found that women and their families rarely had a deep understanding of the cause or implications of their disease. Despite contact with health staff, often since childhood, participants lacked understanding of the severity of their illness and its implications for childbearing. Several information/educational initiatives were developed to improve health literacy and have informed other strategies.

Methods: Content review related to an evidence-base of selected educational resources developed for and by women with RHD, health services and researchers since 2015.

Results: Three resources were selected for review. The first, an information flier on RHD in pregnancy for health professionals, was co-designed by Australasian Maternity Outcomes Surveillance System (AMOSS) researchers, midwives and Aboriginal health practitioners.

The second, 'Sharing a heartbeat' is a two-part video in multiple Aboriginal languages, which explores fertility, pregnancy and family for Indigenous women with RHD. It was written and directed by Aboriginal women in partnership with researchers.

The third is a flipchart with brief text and corresponding illustrations, that guides interaction between health providers and women with RHD in primary health low/middle-income settings. It was developed by *Reach*, a global RHD technical assistance organisation, building on the AMOSS resource.

Discussion: A shared understanding of RHD is essential to improve knowledge and decision-making about the disease and its impact for women's health. The resources described show how research can learn from and inform a collaborative approach to health literacy at both local and global levels.

<http://dx.doi.org/10.1016/j.hlc.2019.05.156>



P30

Beyond Pregnancy: Women With Rheumatic Heart Disease

Geraldine Vaughan^{1,*}, Miriam Wheeler⁵,
Linda Bootle⁴, Vicki Wade³, Sara Noonan³,
Bec Slade³, Elizabeth Sullivan^{2,1}

¹ *University of Technology Sydney, The Australian Centre for Public and Population Health Research (ACPPHR), Ultimo, Australia*

² *University of Newcastle, Faculty of Health and Medicine, Newcastle, Australia*

³ *Menzies School of Health Research, RHD Australia, Darwin, Australia*

⁴ *Aboriginal Maternal Infant Health Service (AMHIS), Western NSW Local Health District, Australia*

⁵ *Auckland City Hospital, Grafton, New Zealand*

Background: For pregnant women with rheumatic heart disease (RHD), the increased risk of adverse health outcomes for themselves and their babies demands a collaborative approach that addresses cultural needs. A high burden of this preventable disease persists among Aboriginal and Torres Strait Islander, Māori and Pacifica women and other vulnerable populations. Research and advocacy initiatives increasingly call for culturally-appropriate models to achieve early assessment and holistic care. The 3rd edition of the Australian RHD Guidelines address these.

Methods: The 'Women with RHD' chapter was developed by a core writing group with multidisciplinary expert input including cultural advice. A literature review supported by co-author referencing found no specific guidelines that address comprehensive models of care for women with RHD, which has specific risks related to underlying social determinants, epidemiology and cardiac pathology.

Results: Optimal outcomes for women with RHD require strategies that commence in childhood. They address transition to adult care, reproductive health, decisions about surgery, and pregnancy planning. Two-way learning and social context are critical to support clinical pathways including high-risk care.

Features that underpin high-quality maternity care are consistent with principles of care for women with RHD: cultural respect and early antenatal review in a women-centred framework that addresses risk and supports continuity of care within the community context.

Discussion: Guidelines for women with RHD need to incorporate principles of care for adolescents, young adults and women from initial diagnosis. Evidence-based care must look to maternity, cardiac, reproductive, Indigenous and primary health standards within a whole-of-life framework.

<http://dx.doi.org/10.1016/j.hlc.2019.05.157>

