Rheumatic Heart Disease in Pregnancy: A Health Services Challenge

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Background: Potential deficiencies in health service delivery for pregnant women with rheumatic heart disease (RHD-P) can escalate risk of poor perinatal outcomes with attendant impact on women and community. This disease of paradox (and inequity) is overall rare in Australia– yet 2-3 per 100 Aboriginal women in the NT journey through pregnancy each year with RHD.

Aim: A mixed methods study explores factors that impact on delivery of care for women with RHD-P. It extends from an NHMRC-funded research study on the impact of RHD-P under the AMOSS, a bi-national (ANZ) surveillance/research system of severe obstetric conditions.

Methods: A quantitative study analyses patterns of surveillance and data collection processes of RHD-P notifications using the AMOSS, with the aim of identifying gaps in effective reporting. A second study involves semi-structured interviews with health professionals working with pregnant women with RHD.

Findings: A review of surveillance methods across 262 sites highlighted multiple cardiac/maternity care pathways matched by health information systems (HIS) with varying degrees of integration. Preliminary themes from interviews with health professionals reinforce concerns regarding HIS. Other systemic barriers include access to timely cardiac care, transport and other services especially in remote regions, lack of interpreter services, transition to adult cardiac care, and gaps in collaborative multidisciplinary care. Other themes include gaps in health literacy and awareness of RHD-P among health providers, and the imperative for culturally appropriate care.

Conclusion: Optimal health care for women with RHD-P is impacted by a complex interplay of structural and attitudinal factors.