

What matters for pregnant women with rheumatic heart disease - perspectives of health service providers: A qualitative study

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March 07, 2024

Abstract

Objective: Rheumatic heart disease (RHD) persists in low-middle-income countries and in high-income countries where there are health inequities. RHD in pregnancy (RHD-P) is associated with poorer maternal and perinatal outcomes. Our study examines health care perspectives of models of care for women with RHD-P. **Design:** Descriptive qualitative study exploring health professionals' perspectives of care pathways for women with RHD-P. **Setting:** Australia **Population:** Nineteen participants from maternal health and other clinical and non-clinical domains related to RHD-P. **Methods:** Thematic analysis of semi-structured interviews. **Results:** A constellation of factors challenged the provision of cohesive women-centred care, related to health systems, workforces and culture. Themes included conduits of care - helping to break down silos of information, processes and access; 'layers on layers' - reflecting the complexity of care issues; and shared understandings - factors that contributed to improved understandings of disease and informed decision-making. **Conclusions:** Pregnancy for women with RHD provides an opportunity to strengthen health system responses, improve care pathways and address whole-of-life health. To respond effectively, structural and cultural changes are required including enhanced investment in education and capacity building - particularly in maternal health - to support a better informed and skilled workforce. Aboriginal Mothers and Babies programs provide useful exemplars to guide respectful effective models of care for women with RHD, with relevance for non-Indigenous women in high-risk RHD communities. For key goals to be met in the context of RHD, maternal health must be better integrated into RHD strategies and RHD better addressed in maternal health.

Title page

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Running title

RHD in pregnancy – health service perspectives

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Tweetable abstract

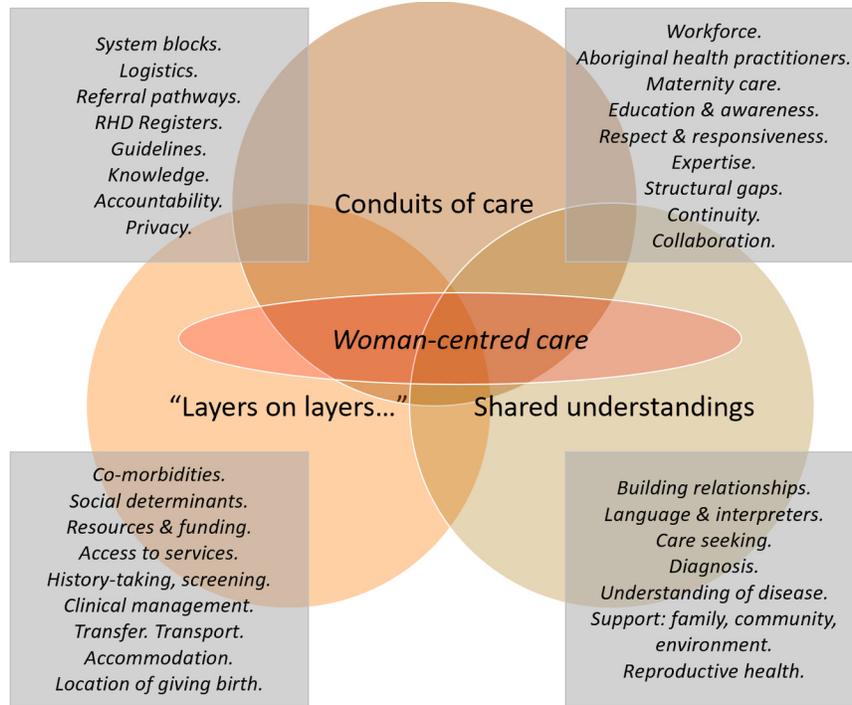
Qualitative study highlights care gaps for women with rheumatic heart disease (RHD). RHD must be better addressed in pregnancy.

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Access to services	Education & awareness. Guidelines	Health information systems	Workforce, health sectors	Integrated care	Clinical management	The big picture
Collaborative trans-disciplinary care						
 Transport	 Knowledge. Awareness. Respect	 Data systems - perinatal, cardiac, community, RHD	 Expertise. Skill. Respect	 Mapping care. Preconception. Pregnancy	 Diagnosis. Transition to adult cardiac & SRH care	 Social determinants - priorities
 Obstetric, Cardiac, other specialist services Medications	 Guidelines	 E-health, paper-based	 Continuity of care. Short-term locums	 Women, families, community. Shared understandings	 Risk assessment. Monitoring. Surgery	 Causes of causes: Housing. Inequity
 Logistics, system blocks. Language	 Checklist. Asking right questions, right way	 Intra/interjurisdictional. Public/private sectors	 Indigenous health practitioners & workers	 Co-morbidity. Chronic disease management	 Secondary prophylaxis. Anticoagulation. Dental	 Global burden
 Built environments	 Education. Curricula	 System blocks. Referral pathways	 Resources	 Vertical v horizontal v diagonal delivery	 Complications. Outcomes	 Advocacy. Initiatives. Changing landscape