

Defining the experiences and needs of  
Australian women with cardiac disease in  
pregnancy and the first year postpartum:  
a mixed methods study

**by Jane Hutchens**

Thesis submitted in fulfilment of the requirements for  
the degree of

**Doctor of Philosophy**

under the supervision of Doctor Jane Frawley and Professor  
Elizabeth Sullivan

## **Certificate of original authorship**

I, Jane Hutchens declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the School of Public Health, Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise reference or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

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## **Statement of contributions to jointly authored works contained in the thesis**

The results from this thesis have been submitted for publication in peer-reviewed journals through six discrete manuscripts, presented in Chapters 4 through 9. For each of these papers, I have been primarily responsible for determining the research question, undertaking the analysis and drafting the manuscript. The contribution to each of the following articles is: Jane Hutchens 80%, Dr Jane Frawley 10%, Professor Elizabeth Sullivan 10%. I take full responsibility in the accuracy of the findings presented in these publications and this thesis.

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*The healthcare experiences of women with cardiac disease in pregnancy and postpartum*  
(Appendix 8)

*Voice & self-advocacy of women with cardiac disease in pregnancy and postpartum* (Appendix  
9)

*Mental health of women with cardiac disease in pregnancy and the first year postpartum*  
(Appendix 10)

*Quality of life of women with cardiac disease in pregnancy and the first year postpartum*  
(Appendix 11)

*The ongoing needs of women with cardiac disease in pregnancy and the first year postpartum*  
(Appendix 12)

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# Abbreviations

AD	Aortic dissection
AF	Atrial fibrillation
AMOSS	Australian Maternity Outcomes Surveillance System
(a)OR	(adjusted) Odds ratio
ARVC/D	Arrhythmogenic right ventricular cardiomyopathy/dysplasia
AS	Aortic stenosis
AIHW	Australian Institute of Health and Welfare
CAQ	Cardiac Anxiety Questionnaire
CARPREG II	Cardiac Disease in Pregnancy database II
CDPP	Cardiac disease in pregnancy and the first twelve months postpartum
CHD	Congenital heart disease
CMY	Cardiomyopathy
DASS	Depression, Anxiety and Stress Scales
ED	Emergency department
DCM	Dilated cardiomyopathy
EF	Ejection fraction
FMD	Fibromuscular dysplasia
GAD	Generalised anxiety disorder
GAD-7	Generalized Anxiety Disorder 7-item measure
GP	General practitioner
HCM	Hypertrophic cardiomyopathy
HCP	Healthcare professional
HD	Heart disease
HDP	Hypertensive disorders of pregnancy
HF	Heart failure
HR	Hazard ratio
HRQoL	Health-related quality of life
ICD	Implantable cardiac defibrillator
IHD	Ischaemic heart disease
IOM	Institute of Medicine

KCCQ	Kansas City Cardiomyopathy Questionnaire
LBW	Low birth weight
LQTS	Long QT syndrome
(L)VAD	(Left) Ventricular assist device
LVEF	Left ventricular ejection fraction
LVNC	Left ventricular non-compaction cardiomyopathy
MACE	Major adverse cardiac event
MACCE	Major adverse cardiovascular and cerebrovascular events
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MGI	Mother-Generated Index
MI	Myocardial infarction
MMR	Maternal mortality ratio
MS	Mitral stenosis
mWHO	modified World Health Organization classification of maternal risk
NIS	National Inpatient Sample
NYHA	New York Heart Association classification of heart failure
PAMI	Pregnancy-associated myocardial infarction
PHQ-9	Patient Health Questionnaire-9
PPC	Person-centred care
PPCM	Peripartum cardiomyopathy
PRO	Patient-report outcome
PROM	Patient-reported outcome measure
PSCAD	Pregnancy-related spontaneous coronary artery dissection
PTSD	Posttraumatic stress disorder
QoL	Quality of life
RCM	Restrictive cardiomyopathy
RHD	Rheumatic heart disease
ROPAC	Registry Of Pregnancy And Cardiac disease
(R)TA	(Reflective) thematic analysis
SCAD	Spontaneous coronary artery dissection
SD	Standard deviation

SGA	Small for gestational age
SMM	Severe maternal morbidity
STEMI	ST-segment elevation myocardial infarction
(S)VT	(Supra) Ventricular tachycardia
UKOSS	United Kingdom Obstetric Surveillance System
USA	United States of America
VF	Ventricular fibrillation
WHO	World Health Organization
WHOQoL-Bref	World Health Organization Quality of Life instrument, brief form

### **Cardiac risk assessment tools for pregnancy and postpartum**

CARPREG II	Canadian risk index for predicting maternal pregnancy outcome in women with all types of cardiac disease
mWHO	modified World Health Organization: classification of maternal risk used to estimate morbidity and mortality in pregnant women with cardiovascular disease
Zahara	European risk scoring system for predicting the pregnancy complications in women with CHD
<b>Other</b>	
NHYA	New York Heart Association's functional classification of heart failure

# Abstract

## **Background**

Cardiac disease in pregnancy and the first year postpartum (CDPP) is a leading cause of maternal mortality. CDPP is associated with significant serious maternal morbidity encompassing physical, psychosocial, emotional and functional wellbeing.

## **Aims**

To give voice to women who have or had CDPP, to characterise and enhance the understanding of women's experiences and the impact on their quality of life, mental health and mothering, and to describe their needs to identify opportunities to improve women's outcomes.

## **Methods**

This thesis uses a three-phase exploratory sequential mixed methods research design. Study 1 involved in-depth semi-structured interviews to provide the foundation and establish central themes. Study 2 was an online survey that expanded upon Study 1 findings on the impact of CDPP on women's quality of life, mental health, and experiences of mothering, and the needs of women with CDPP. Study 3 explores the needs of women with CDPP via focus groups.

## **Results**

Women's healthcare experiences did not meet their expectations or needs and were characterised by a lack of person-centred care, and women feeling dismissed and powerless. Self-advocating was difficult and often unsuccessful, which had negative cardiac and psychological outcomes. There was a lack of co-ordinated care, continuity of care and a lack of responsiveness of the healthcare system to provide fit for purpose health care for women with complex disease who are pregnant or new mothers.

Women experienced anxiety, depression and post-traumatic stress subsequent to their CDPP, with DASS-21 results indicating a higher prevalence of mental health conditions when compared with Australian norms. Quality of life measured by the WHOQoL-Bref was lower than Australian

norms in domains such as health satisfaction, physical health, psychological health, and social relationships.

Mothering experiences with CDPP were characterised by a lack of healthcare professional recognition of the centrality of mothering to women's lives, the importance of future pregnancies and breastfeeding, disrupted connection with their infant, and being restricted in what they could do. The results of the needs assessment and focus groups provided strong patient support for a structured peer support program, incorporation of counselling referrals into routine care and equity of access to a cardiac link nurse.

### **Conclusion**

Women with CDPP have complex experiences that impact their mental health, quality of life and experiences of mothering that continued well beyond pregnancy and the first year postpartum. Health care did not meet their needs or expectations. This research has produced multiple implications and recommendations for stakeholders.