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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.

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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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Reports prepared for the NSW Heart Foundation

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)

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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

Other

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.

Chapter 1: Background

1.1 Chapter introduction

The physiological changes and demands of pregnancy can expose previously undiagnosed cardiovascular conditions, provoke de novo disease and exacerbate known pre-existing disease. Cardiac disease in pregnancy and the first year postpartum (CDDP) is a leading cause of maternal morbidity and mortality. Up to 4% of pregnancies are complicated by cardiac disease, with further cases in the first year postpartum and evidence of increasing prevalence (Regitz-Zagrosek et al., 2018). There is a lack of comprehensive data on the healthcare experiences of women with CDPP; including the impact of CDPP on women's quality of life, mental health and experiences of mothering; and the needs of women. A recent meta-synthesis confirmed the paucity of research on women's experiences and highlighted the need for greater engagement with women and the development of models of care that are responsive to women's needs, knowledge and desired outcomes (Dawson et al., 2018). This introductory chapter presents an overview of CDPP and provides the context for this thesis. The chapter outlines definitions and epidemiology of CDPP, and characteristics of pregnancies and births in Australia and describes the models of cardiac and maternal care within the Australian health care system in order to provide a scaffold for the following chapters. This chapter concludes by providing the thesis research aims, questions, significance and structure.

1.2 Epidemiology of cardiac disease in pregnancy and postpartum

1.2.1 Definition of CDPP for this thesis

The term cardiac disease in pregnancy and postpartum (CDPP) includes pre-existing or newly diagnosed cardiac disease in pregnancy or in the first 12 months postpartum.

CDPP includes a variety of structural heart and aortic diseases, cardiomyopathies, rhythm disorders, ischaemic heart disease, and arterial dissections. Classification of diseases varies; for this thesis disease are categorised as acquired, genetic, or congenital (present at birth), noting that some conditions may be in more than one category (e.g., supraventricular tachycardiac may be acquired or genetic). Further, some conditions currently understood as acquired may have risk factors that are genetic, for example, fibromuscular dysplasia is often considered to be a genetic condition and it is an important risk factor for acquired condition spontaneous coronary artery dissection.

The World Health Organization (World Health Organization, 2010b) defines the postpartum period as birth to 42 days; however, for some conditions late postpartum presentations of disease occurs after 42 days postpartum. For example, a current proposed timeframe for pregnancy associated spontaneous coronary artery dissection (PSCAD) is categories of antepartum, early postpartum (up to 6 weeks after delivery), late postpartum (up to 12 months), and very late postpartum (within 12 and 24 months) (Vijayaraghavan et al., 2014). Similarly, peripartum cardiomyopathy may present up to 12 months postpartum (Wu et al., 2017). This thesis is examining cardiac disease up to 12 months postpartum.

Following are the core diseases in each category, noting that CDPP does not include hypertensive disorders, pre-eclampsia, eclampsia or thromboembolic disorders.

Acquired: atrial fibrillation, coronary artery disease, idiopathic cardiomyopathy, peripartum cardiomyopathy, pregnancy-associated spontaneous coronary artery dissection, myocardial infarction, pericarditis, rheumatic heart disease

Congenital: atrial/ventricular septal defect, bicuspid aortic valve, coarctation and stenosis of the aorta, congenitally corrected transposition great vessels, dextrocardia, Fontan circulation, left ventricular non-compaction syndrome, mitral valve prolapse, patent ductus arteriosus, patent foramen ovale, prolapsed pulmonary valve, pulmonary stenosis, tetralogy of Fallot, transposition of great arteries, truncus arteriosus, valve prolapse, regurgitation and/or stenosis

Genetic: arrhythmogenic mitral valve prolapse, arrhythmogenic right ventricular dysplasia /cardiomyopathy, hypertrophic cardiomyopathy, long QT syndrome, supraventricular tachycardia

CDPP is associated with significant serious maternal morbidity and in some cases, maternal death. The morbidity experienced by women encompasses physical, psychosocial, emotional, cultural and functional wellbeing. Further, whilst not included in this thesis it is noted that the impact of CDPP is felt by women’s partners, children, other family, friends and the broader community as her participation is likely reduced because of her disease and experiences.

1.2.2 Pregnancies and births in Australia

Number of births and deaths

In 2019 there were 303,054 live births, 2,183 stillbirths (7.2 deaths per 1,000 births) and 714 neonatal deaths (2.4 neonatal deaths per 1,000 births) in Australia (Australian Institute of Health and Welfare, 2021a). A stillbirth in Australia is defined as the loss of a pregnancy of at least 20 weeks gestation or weighing at least 400gm at birth; neonatal deaths are all registered deaths occurring within 28 days of birth (Australian Institute of Health and Welfare, 2021a). The rate of stillbirths is relatively stable.

Culture and identity

Approximately 6.0% (18,086) of babies were Indigenous, and 4.8% (14,241) mothers were Indigenous. Most mothers (64.1%) were born in Australia, and of those who weren’t the most common countries of birth were India (5.4%), China (3.2%) and New Zealand (2.8%) (Australian Institute of Health and Welfare, 2021a). Indigenous and overseas-born mothers may have specific requirements for maternal care to be culturally appropriate and safe.

Maternal risk factors

General maternal risk factors of obesity, diabetes, hypertension and smoking are all applicable in cardiac disease.

Maternal age is a key risk factor for maternal and infant morbidity and mortality, with both ends of the age spectrum representing the highest risk. In Australia the number of older mothers is increasing while the numbers of younger mothers are decreasing. In 2019 the mean age of mothers was 30.9 years except for Indigenous mothers who had a mean age of 26.2 years, an increase from 25.2 in 2007 (Australian Institute of Health and Welfare, 2020a, 2021a). Compared with non-Indigenous mothers, Indigenous mothers were eight times more likely to be teenagers (Australian Institute of Health and Welfare, 2020a). The proportion of mothers aged 35 years and over has increased from 22.3% in 2007 to 25.2% in 2019 and the average age of first-time mothers also increased, from 27.9 in 2009 to 29.4 in 2019 (Australian Institute of Health and Welfare, 2021a).

In 2019 21.1% of mothers were classified as obese (BMI of 30.0kg/m^2 or more) and 26.4% overweight (BMI 25.0 to 29.90kg/m^2) (Australian Institute of Health and Welfare, 2021a). Overweight and obesity increased with age, with 52.5% of mothers aged 40 years or more classified as overweight or obese. Gestational diabetes affected 11.3% (33,867) of mothers and was more prevalent with increasing age (17.8% in mothers 40 years and older compared to 5.0% for mothers aged under 20 years). The rate of pre-existing (chronic) hypertension has been between 3% and 4% since 2014, with older mothers more likely to have chronic and gestational hypertensions than younger women (Australian Institute of Health and Welfare, 2021a). Both chronic and gestational hypertension are associated with increased concurrent and subsequent cardiovascular disease risk (Lo et al., 2020; Redon et al., 2016)

Risk is unevenly distributed, for example, in addition to being more likely to be younger and living in lower socioeconomic status areas, Indigenous mothers are 1.1 times more likely to have gestational diabetes and 4 times as likely to have pre-existing diabetes and 3 times as likely to have gestational hypertension. Babies born to Indigenous mothers are 1.6 times as likely to be admitted to a neonatal intensive care unit and 1.7 times as likely to be stillborn, and twice as likely to die within the first 28 days of life (Australian Institute of Health and Welfare, 2020a).

1.2.3 Prevalence and outcomes of CDPP

Cardiac disease in pregnancy and postpartum is under-researched in Australia and internationally. International prevalence estimates range from 1% to 4% of all pregnancies (Regitz-Zagrosek et al., 2018) and up to 16% of pregnancies in women with previous cardiac conditions (Silversides et al., 2018). In the absence of Australian prevalence data, applying the international prevalence estimate to Australian births in 2019 produces an estimated 3,030 to 12,122 women potentially affected by CDPP (Australian Institute of Health and Welfare, 2021a). There is evidence that the prevalence of cardiac disease in pregnancy is increasing; this may be due to the demographic shift in childbearing in middle and high-income countries to older aged mothers, growing rates of obesity, cardiovascular disease, diabetes, hypertension and other medical conditions as well as lifestyle risk factors such as diet and exercise (Mehta et al., 2020).

Additionally, increasing rates of congenital heart disease survivors having children are impacting the prevalence of pregnancy related heart disease (McClure et al., 2011). In developed nations congenital heart disease (CHD) is the most common cardiovascular disease present during pregnancy (75–82%), and rheumatic valvular disease, caused by un- or under-treated Group A *Streptococcus* infection, is the most common in emerging nations (56–89%) (Regitz-Zagrosek et al., 2018).

Maternal death is the death of a woman during pregnancy or within 42 days of the end of pregnancy, irrespective of the duration and outcome of the pregnancy, and includes any cause related to or aggravated by pregnancy or the management of pregnancy. Maternal death is categorised as direct and indirect. Direct causes of maternal death are those due to obstetric complications or their management. Indirect causes of maternal death include death resulting from conditions and diseases aggravated by physiological effects of pregnancy, excluding obstetric causes; cardiac disease is categorised as an indirect cause of maternal death.

The incidence of maternal death is expressed as the maternal mortality ratio (MMR). The MMR includes direct, indirect and not classified maternal deaths (excluding coincidental deaths and deaths awaiting classification) and is expressed as per 100,000 women giving birth. Between 2010 and 2019, the MMR in Australia was relatively stable, ranging from between 5.0 to 8.4 per 100,000 women giving birth (Australian Institute of Health and Welfare, 2019b).

In Australia, cardiovascular disease was the leading cause of maternal death between 2010 and 2019 and was responsible for 14% of all maternal deaths and 28% of indirect maternal deaths (Australian Institute of Health and Welfare, 2021a). Maternal deaths that are recorded only up to 42 days postpartum omit late presenting cardiac cases, in particular pregnancy associated spontaneous coronary artery dissection (PSCAD) and peripartum cardiomyopathy (PPCM), thus the data underrepresents incidence. Cardiovascular disease is a leading cause of maternal death in developed and developing nations and is predicted to increase further (Ramlakhan et al., 2020).

Maternal morbidity is also significant with up to 26% of women with cardiac disease hospitalised during pregnancy (Roos-Hesselink et al., 2013). Of 5,739 women enrolled in the Registry Of Pregnancy And Cardiac disease (ROPAC) between 2007 and 2018, 17% experienced obstetric complications (Roos-Hesselink et al., 2019). (The ROPAC is an international, prospective, observational registry of pregnant women with congenital heart disease, valvular heart disease, cardiomyopathy, or ischaemic heart disease. It was established in 2007 by the European Society of Cardiology (ESC) with the objectives to research the epidemiology, treatment and outcomes for registrants across more than 60 countries. This information can then be used to improve management and outcomes.) Maternal and foetal/neonatal events are correlated, with offspring complications for 20% of women with cardiac disease in pregnancy (Siu et al., 2001).

There are little data on the overall prevalence of cardiac disease in pregnancy and postpartum in Australia. A recent prospective population-based study in Australia and New Zealand reported 311 confirmed cases of rheumatic heart disease (RHD) in pregnancy over 2 years (4.3/10,000 women giving birth; 0.04%) (Sullivan et al., 2020). An earlier study of rates of prosthetic heart valves in NSW reported a rate of 1.1 per 10,000 pregnancies (Lawley et al., 2014).

Cardiovascular disease in general is a major cause of morbidity and mortality for Australian women with an estimated 510,000 (4.8%) Australian women aged 18 and over with heart and or vascular disease in 2017-2018 (Australian Institute of Health and Welfare, 2019a). Overall rates of hospitalisation for cardiovascular disease in women fell between 2006-07 and 2015-16, however, it rose by 11.0% for women aged 25-34 and by 4.7% for women aged 35-44. These are reproductive years and it is possible that pre-existing heart disease could worsen during pregnancy, putting both mother and infant at risk.

1.3 Models of care and the health system in Australia

1.3.1 The health system in Australia

Australian healthcare is underpinned by Medicare, a universal public health and medical insurance scheme funded by tax-payers. Public patients in public hospitals receive free treatment but are unable to choose their doctor. Medicare also provides part or full rebates for general practitioner and specialist medical consultations in the private practice setting in the community. Public outpatient clinics are available; however, specialist services are restricted to major metropolitan hospitals and face resource limitations. Some services are only available in the public system, such as specialist genetic cardiac disease clinics. Allied health services may be available privately or in the public health system, though the latter has capacity limitations.

1.3.2 Maternity models of care

Models of antenatal care

Options available vary according to availability, geography and cost. An expectant mother can receive antenatal care through one or a combination of; obstetrician, midwife, GP shared-care, and doula, with obstetricians and midwives available in both public and private health systems. Almost all mothers receive antenatal care. In 2019, 94.7% had five or more antenatal visits, and 76.7% had their first visit in the first trimester (Australian Institute of Health and Welfare, 2021a); however, in 2017 8% did not receive antenatal care until after 20 weeks gestation (Australian Institute of Health and Welfare, 2020b). Mothers living in lower socioeconomic status (SES) areas, were aged under 20 years, had a parity of four or more or who smoked were less likely to attend antenatal care in the first trimester of pregnancy (Australian Institute of Health and Welfare, 2021a).

In 2019 the majority of mothers gave birth in a hospital labour ward (97%), with a small percentage birthing in a birth centre (2.3%), at home (0.3%) or in other settings including in transit to the hospital (0.6%) (Australian Institute of Health and Welfare, 2021a). Seventy-five percent of hospital births were in public hospitals.

Mode of birth

Most Australian women (64%) have vaginal births; however, the proportion of caesarean sections is high (36%) and continuing to rise (Australian Institute of Health and Welfare, 2021a). In the period 1991 to 2017, caesareans rose from 18% (AIHW, 2014) to 35%, and vaginal births without intervention fell from 70% to 53% (AIHW, 2019a). In comparison, in 2017 the average rate for caesarean sections in the Organisation for Economic Co-operation and Development (OECD) was 28.1%; the United States was 32.0% (Hamilton BE et al., 2018), the United Kingdom 27.4%, New Zealand was 27.4%, and the rate for Israel was 15.9% (OECD, 2019).

Mothers with medical conditions

Mothers with acute or chronic medical conditions require additional intervention and support during pregnancy. Specialist services are high-risk obstetric clinics in public hospitals, maternal-foetal medicine specialists or obstetric physicians in public or private services. These services are limited to large tertiary referral hospitals in the major metropolitan regions.

1.3.3 Cardiac models of care

Acute cardiac care requires specialist services, typically in tertiary referral hospitals, though patients may be initially stabilised at lower-level facilities before transfer to a specialist service. Patients using public acute services may transfer to private services for ongoing management or may attend limited public outpatient services. Specialised services such as review of implantable devices by a technician may only be available through private clinics.

A review of access to Australian cardiac services found that overall, 71% of Australians lived within a Cardiac ARIA index category 1A location (access by road to a major referral hospital with a cardiac catheterisation laboratory and to all aftercare services within 1 hour) (Clark et al., 2012). This result reflects that Australia is highly urbanised with 66.9% of people living in major cities in 2021 (Australian Bureau of Statistics, 2022).

A study of rural and remote areas in Western Australia identified that 77% of cardiac rehabilitation services were hospital-based with no service providing a comprehensive home-based or alternative method of program delivery (Hamilton et al., 2018). Only 50% of rural and 33% of remote cardiac programs had face-to-face access to multidisciplinary support.

Access to care does not equate to service use. A report on the transition from acute care to community services for people with coronary disease in New South Wales and Victoria found that 44% of patients had no cardiologist review within two years of hospitalisation for a cardiac event (Australian Institute of Health and Welfare, 2018). People in the most disadvantaged group were more unlikely to attend the GP than those in the least disadvantaged group (30.9% vs. 11.8%).

1.3.4 Cardio-obstetrics specialist services

Cardio-obstetrics clinics and units facilitate multidisciplinary, co-ordinated care of women with CDPP, and while mostly only available to metropolitan areas in high-income countries and typically limited to short-term postpartum care, they are showing improved outcomes for women and infants (Magun et al., 2020; Quiñones et al., 2021; Sliwa & Anthony, 2016). In

Australia there are presently no cardio-obstetric wards or units, but there are clinics in some capital cities (in particular, Brisbane and Melbourne). In addition, metropolitan tertiary hospitals may have a maternal-foetal medicine department and cardiac physicians, though availability is likely to be less than required.

1.4 Aims and scope of thesis

1.4.1 Research aim

The aim of this thesis is to give voice to women who have or had CDPP, to characterise and enhance the understanding of women's experiences of healthcare services, the impact of CDPP on their quality of life, mental health and experiences mothering, and to describe their needs in order to identify opportunities to improve patient outcomes. This knowledge can then be used to inform future research and the development of clinical services and guidelines to facilitate person-centred care and awareness of Australian women giving birth and living with cardiac disease.

1.4.2 Research questions

To achieve the above aim this project will answer five research questions as follows.

1. What are the healthcare experiences of women who have CDPP?
2. What is the impact of having CDPP on women's mental health?
3. What is the impact of having CDPP on women's experience of mothering?
4. What is the impact of having CDPP on women's quality of life?
5. What are the needs of women with CDPP?

1.4.3 Significance and scope of thesis

Cardiac disease in pregnancy and the first twelve months postpartum is associated with significant morbidity and is a leading cause of maternal mortality. The prevalence and complexity of CDPP is increasing. Further, beyond the initial acute cardiac/obstetric event, women have lifelong conditions that are expected to reduce longevity and functional capacity, and negatively impact on quality of life. Despite this, there is a paucity of research and data on women's experiences and scant or no resources and support options specifically designed by and for women with cardiac disease in pregnancy and postpartum.

The significance of this research is that it provides unique data on the experiences and needs of women with CDPP. This knowledge can be used to provide an evidence-base to inform the future research and development of clinical services and guidelines. These findings will facilitate person-centred care and awareness of Australian women giving birth and living with cardiac disease.

1.4.4 Thesis structure

This is a thesis by compilation. The findings from this thesis have resulted in journal publications that are presented here in relevant chapters. The overall structure of the thesis is as follows.

Chapter 1 provides background knowledge about models of cardiac and maternity care and the health system in Australia, definitions and prevalence of cardiac disease in pregnancy and the first year postpartum, and pregnancies and births in Australia. In addition, it describes the aims, objective, scope and significance of this research.

Chapter 2 reviews the current international literature relating to CDPP, both epidemiological data on CDPP and women's experiences of CDPP which includes mental health, mothering and quality of life.

Chapter 3 describes the theoretical framework, methodology and procedures that were employed to conduct this study. Details of the study aims, design, study population, recruitment, data collection, management and analysis procedures, and ethical considerations are provided.

Chapter 4 presents results from Study 1 and explores the healthcare experiences of women with CDPP with a focus on person-centred care. The results for this chapter have been published in *Health Expectations*.

Chapter 5 presents results from Study 1 and explores the challenges and complexity of self-advocating within the healthcare setting, especially at a time of physical and psychological vulnerability. Barriers to self-advocacy and the subsequent negative cardiac and psychological outcomes experienced when self-advocacy was impeded. The results for this chapter have been submitted for publication with the *International Journal of Qualitative Studies on Health and Well-being.*

Chapter 6 presents results from Study 1 that analyse women's experiences, mental health outcomes, changes to self-identity and isolation and connection following CDPP. The results for this chapter have been published in *BMC Pregnancy and Childbirth*.

Chapter 7 presents an analysis of women's experiences of mothering with cardiac disease from Study 1. Themes describe women's distress at separation from her child, cessation of breastfeeding, advice to have no further children, the restrictions in function she experienced and the primacy of her identity and role as mother. The results for this chapter have been submitted for publication with *BMC Pregnancy and Childbirth*.

Chapter 8 presents the results of the Mother-Generated Index survey which revealed the largely negative impact of CDPP on women's experiences mothering and other aspects of her life such as reduced longevity, inability to have more children or breastfeed, the physical limitations imposed by their condition, and managing their health. The MGI is a mothering-specific patient-reported outcome measure and to my knowledge this adaptation of the MGI in this study for women with cardiac disease, chronic health and covering many years postpartum is unique. The results for this chapter are being prepared for submission for publication.

Chapter 9 presents the results from Study 2, and analyses the generic and health-related quality of life assessments, and generic and health-specific mental health assessments for women who have had CDPP. The results for this chapter have been have been submitted for publication with *BMC Pregnancy and Childbirth*.

Chapter 10 describes the results of a brief needs assessment and follow-up focus groups, outlining the key areas women identified as priorities for enhancing care and outcomes.

Chapter 11 discusses the implications of the findings of this thesis in the context of previous research, identifies limitations to the study, and highlights important issues relevant to the research aims and objectives. This chapter also identifies areas for future research.

Chapter 12 summarises the significant findings from this thesis and recommends research agendas and projects that may be developed from the results of this research project.

1.5 Chapter summary

This chapter provided the background knowledge about models of cardiac and maternity care and the health system in Australia. Further, it defined CDPP and briefly described the prevalence and outcomes of CDPP, and established the research aims and structure of this thesis.

Chapter 2: Literature review: cardiac disease in pregnancy and the first twelve months postpartum

2.1 Chapter introduction

This chapter provides a narrative review of the literature on cardiac disease in pregnancy and the first twelve months postpartum (CDPP). This review aims to provide a summary of the published literature on the prevalence and outcomes of CDPP, as well as women's lived experience and needs. This literature review informs and provide the framework for the thesis, and is presented in two parts, as follows.

Part A provides an overview of the literature on the prevalence and outcomes for women with CDPP and serves to contextualise the complexity and diversity of this population as well as highlight the significant morbidity and mortality involved. The heterogeneity of both the population and research to date precludes undertaking a meta-analysis and while this section includes systematic reviews, some are small and consist of case reports and series.

Part B provides a review of the limited literature on women's lived experiences of CDPP. The focus of this section is the impact of CDPP on women's mental health, quality of life, and experiences mothering. This section informed the decision to examine these aspects of women's lives in more detail and to provide an introductory analysis of the needs of women who have CDPP.

2.2 Methods

A review of the literature examining the prevalence, outcomes and women's experiences of CDPP was undertaken for the most common conditions involved.

2.2.1 Search strategy

The following key terms were used to search the following databases, MEDLINE, CINAHL, SCOPUS and Google Scholar for articles published up to 15 years ago relating to ***Part A*** of the literature review (Prevalence and outcomes of cardiac disease in pregnancy and the first twelve months postpartum).

- pregnan*, antepartum, peripartum, postpartum, antenatal, perinatal, postnatal, mother*, matern*

- cardiac, congenital heart disease, CHD, Fontan, spontaneous coronary artery dissection, pregnancy associated spontaneous coronary artery dissection, ischaemic heart disease, myocardial infarction, acute coronary syndrome, heart failure, cardiomyopathy, myocardial infarction, peripartum cardiomyopathy, aortic dissection, vascular dissection, arrhythmia, valvular disease, rheumatic heart disease, RHD, structural heart disease, heart transplant, chemotherapy, implantable cardiac devices, ICD

- maternal morbidity, maternal mortality, SMM, severe maternal morbidity, prevalence, epidemiology, outcomes, neonatal, infant

The following key terms were used to search the following databases, MEDLINE, CINAHL, SCOPUS and Google Scholar for articles published up to 15 years ago relating to ***Part B*** of the literature review (The lived experience of having cardiac disease in pregnancy and the first twelve months postpartum).

- pregnan*, antepartum, peripartum, postpartum, antenatal, perinatal, postnatal, mother*, matern*, outcomes, neonatal, infant

- experienc*, QoL, quality of life, mental health, anxiety, depression, posttraumatic stress disorder, PTSD, mothering, chronic illness

2.2.2 Inclusion and exclusion criteria

Part A: Prevalence and outcomes. Studies were included if they were peer-reviewed, contained an abstract and were published in English. Studies were limited to the previous 15 years. Studies and articles were excluded if they were duplicates, commentaries, individual case reports, works that had not adopted systematic research design or data reporting procedures, and those concentrating on treatment options. Articles were also excluded if they were not published in English and if the data could not be disaggregated based on pregnancy and postpartum status.

A biographical, journal and author search was also conducted, and 5 articles were included that were published more than 15 years ago as they are considered seminal [e.g., PPCM research by Fett et al. (2005)].

Part B: Lived experience. Both qualitative and quantitative studies were included, (including case reports) if they contained an abstract and were published in English. Hand searching identified a significant number of additional articles included in this review.

2.2.3 Data extraction

The data were extracted into a Microsoft Excel file.

Data extraction for Part A included: author(s), title, journal, year, country, number of participants, type of article, methods, outcome measures, cardiac conditions and main findings (see Table 2.1).

Data extraction for Part B included: author(s), title, journal, year, country, number of participants, type of article, methods, cardiac conditions where relevant and main findings (see Tables 2.3, 2.4, 2.5, and 2.6).

2.3 Results

Part A: Prevalence and outcomes of cardiac disease in pregnancy and the first 12 months postpartum

2.3.1 Overall prevalence

Estimating the prevalence of individual cardiac diseases in pregnancy and postpartum presents several challenges, including lack of population studies of rare conditions, newly emerging diagnoses, incorrect diagnosis, and study periods that do not cover the relevant pregnancy-related period to 12 months postpartum (for example, only including data from the birth admission or first 42 days postpartum) plus composite results that do not specify the individual conditions included. The following review of the literature focuses on the main diseases and highlights some of the challenges and gaps in the data.

The current limitations in accuracy and breadth of prevalence data of individual cardiac diseases clearly impacts the ability to accurately estimate aggregate CDPP prevalence. Recent international estimates are that 1 to 4% of pregnancies are complicated by cardiac disease (Regitz-Zagrosek et al., 2018) with a preponderance of rheumatic (valvular) heart disease and peripartum cardiomyopathy (PPCM) in low-middle-income countries and congenital heart disease and myocardial infarction in high-income countries (Regitz-Zagrosek et al., 2018).

A 2017 study used the National Inpatient Survey (NIS) database from 2003 to 2012 to investigate prevalence, trends, and major adverse cardiac events (MACEs) for 81,295 patients with heart disease (HD) in pregnancy (MACEs included a combination of in-hospital death, myocardial infarction (MI), heart failure (HF), stroke, embolic events, or cardiac complications of anaesthesia) (Lima et al., 2017). Congenital heart disease (CHD) was the most frequent type of HD (41.8%), followed by valvular HD (30.9%), all cardiomyopathy (CMY) (20.8%), and pulmonary hypertension (PH) (6.5%). MACE was most frequent in CMY (44.0%) and lowest in CHD (6.2%). The authors noted overall HD prevalence increased in the study period by 24.7% and MACE increased by 18.8%. *Table 1* lists the prevalence studies for CDPP, with only two meta-analyses available at the time of writing. The variability of findings illustrates challenges in estimating prevalence. Note, some of the studies listed are for specific conditions within the broader categories.

Table 2.1*: Prevalence of cardiac disease in pregnancy and postpartum*

Author, year	Study setting	Country	Sample size	Study period	Prevalence per 100,000 pregnancies
Congenital heart disease					
Opotowsky et al., 2012	National Inpatient Sample	USA	42,602,106	1998-2007	71.6
Thompson et al., 2015	National Inpatient Sample	USA	12,524,118	2000-2010	90
Owens et al., 2018	Statewide Planning and Research Co-operative System	USA	2,284,044	2000-2014	59.9
Schlichting et al., 2019	National Inpatient Sample	USA	22,881,691	2008-2013	77.5
Valvular heart disease					
Lima et al., 2019	National Inpatient Sample	USA	15,273,247	2010-2014	54.95 *All valvular disease* total 8394
Minhas et al., 2021	National Inpatient Sample	USA	11,284,712	2016-2018	180.3 *All valvular disease* total 20,349
Sullivan et al., 2019	Australasian Maternity Outcomes Surveillance System	Australia and New Zealand	Est. 723,356	2013-2014	43 *Rheumatic heart disease only*
Pregnancy associated myocardial infarction (may include pregnancy associated spontaneous coronary artery dissection)					
Gibson et al., 2017	Meta-analysis	Global	75,570,508	1960-2011	3.34
Smilowitz et al., 2018	National Inpatient Sample	USA	55,402,209	2002-2004	8.1
Tripathi et al., 2019	National Inpatient Sample	USA	43,437,621	2005-2014	8.7
Dongarwar et al., 2021	National Inpatient Sample	USA	45,498,605	2009-2018	11.1

Pregnancy associated spontaneous coronary artery dissection						
Faden et al., 2016	National Inpatient Sample	USA	4,363,343	2008-2012	1.8	
Beyer et al., 2020	Nationwide readmissions database	USA	18,151,897	2010-2015	2.1	
Aortic dissection						
Nasiell et al., 2009	Single hospital	Sweden	81,284	1999-2007	1.45	
Nasiell et al., 2010	National registry	Sweden	2,087,505	1987-2007	1.39	
Kamel et al., 2016	Hospitals in 3 states	USA	6,566,826	2005-2013	0.55	
Beyer et al., 2020	Nationwide readmissions database	USA	18,151,897	2010-2015	1.1	
Arrhythmias						
Vaidya et al., 2017	National Inpatient Sample	USA	57,315,593	2000-2012	68	*All arrhythmias*
Vaidya et al., 2017	National Inpatient Sample	USA	57,315,593	2000-2012	22	*Paroxysmal supraventricular tachycardia only*
Lee et al., 2020	National insurance Sample	Taiwan	2,387,588	2001-2012	33	*Paroxysmal supraventricular tachycardia only*
Vaidya et al., 2017	National Inpatient Sample	USA	57,315,593	2000-2012	27	*Atrial fibrillation only*
Chokesuwattanaskul et al., 2019	Meta-analysis	Global	301,638	All up to 2018	300	*Atrial fibrillation only*
Heart failure						
Mogos et al., 2018	National Inpatient Sample	USA	50,995,050	2001-2011	112.3	*All HF, pregnancy to 6 weeks postpartum*
Barasa et al., 2017	National Inpatient, Cause of Death and Medical Birth Registries	Sweden	1,378,351	1997-2010	17.5	*All HF, including PPCM; not all cases specified cause* Last 3 months of pregnancy to 6 months postpartum

Peripartum cardiomyopathy						
Kolte et al., 2014	National Inpatient Sample	USA	33 118 166	2004-2011	103	*Last month of pregnancy to 5 months postpartum*
Behrens et al., 2019	National registries	Denmark	2,078,822	1978-2001	6.06	*Last month of pregnancy to 5 months postpartum*
Masoomi et al., 2018	Nationwide readmissions database	USA	1,242,303	2013	45.72	*Birth admission to 3 months postpartum*
Lee et al., 2018	National insurance database	South Korea	1,404,551	2010-2012	57	*Birth admission to 12 months postpartum*
Ersboll et al., 2017	National registry	Denmark	619,084	2005-2014	9.85	*All of pregnancy to 12 months postpartum*
Wu et al., 2017	National insurance database	Taiwan	3,506,081	1997-2011	26.38	*All of pregnancy to 12 months postpartum*

Congenital heart disease

Congenital heart disease includes a diverse range of anomalies and severity, from a small, uncomplicated or repaired atrial septal defect though to Tetralogy of Fallot, Transposition of the great arteries and Fontan procedure (Warnes et al., 2001). Understanding the prevalence of all adults with CHD helps estimate current and future pregnancy rates. Advances in modern imaging, surgical techniques, postoperative care and medical management have markedly improved survival rates; 85% of babies born with CHD are now expected to survive (Bishop et al., 2018) and adults now outnumber children, with 66% of the CHD population in Canada being adult (Marelli et al., 2007). The survivorship of people with severe CHD is also increasing, from 9% in 2000 to 14% in 2010 (Bishop et al., 2018; Marelli et al., 2007; Wu et al., 2020). In Japan from 1997 to 2007, there has been an estimated increase of 9000 adults with CHD every year (Shiina et al., 2011). Nicolae et al. (2019) estimated there is about 72,000 adults with CHD in Australia and 1:150 adults in the next decade will have CHD.

Data for the prevalence for CHD in pregnancy is limited, in part due to the relative recency of women with CHD reproducing, the small numbers involved and different levels of access to diagnosis in developing countries. Nonetheless, CHD is the most common cause of CDPP in developed nations (Regitz-Zagrosek et al., 2018) and in a large international study on cardiac disease in pregnancy, 66% of cases involve CHD (Roos-Hesselink et al., 2013). Recent population studies in the United States report a prevalence of CHD in pregnancy of 60.0 to 90 per 100,000 pregnancies (Owens et al., 2018; Schlichting et al., 2019; Thompson et al., 2015).

In the USA, the rate of births for women with CHD increased by 34.9% compared to 21.2% for women without CHD from 1998 to 2007 (Opotowsky et al., 2012). A Canadian study reported that from 1992 to 2004, 5,641 (37.9%) of a total of 14,878 women with CHD experienced 10,809 pregnancies, of whom 4,551 (80.7%) experienced at least one birth and 2,528 (44.8%) experienced at least one birth and/or abortion (Bottega et al., 2019). The absolute numbers and rates of pregnancies and deliveries per 1,000 eligible women with CHD increased from 720 to 955 and 458 to 640, respectively while the rate of abortion decreased (Bottega et al., 2019).

Valvular disease and valve replacements

Valvular heart disease can be congenital or acquired, and both affect maternal and infant morbidity and mortality (Sliwa et al., 2015). One or multiple valves may be affected, the valve may be stenotic or regurgitant, a mechanical (prosthetic) or tissue valve replacement may be insitu, it may be isolated single-valve disease or part of complex cardiac disease with ventricular dysfunction, dysrhythmia and aortopathy.

The characteristics of valvular heart disease during pregnancy varies significantly worldwide. Recent population studies from the US reported rates of 54.96 to 180.3 per 100,000 (Lima et al., 2019; Minhas et al., 2021). The Registry of Pregnancy and Cardiac disease (ROPAC) studies found that valvular disease is the most prevalent diagnosis (55%-56%) in pregnant women in developing nations (Roos-Hesselink et al., 2019; van Hagen et al., 2018; van Hagen et al., 2016). The prevalence of acquired valvular disease is largely due to rheumatic heart disease (RHD) which has a population prevalence of 11.3% - 26.1%, with higher rates in low-income countries (Noubiap et al., 2019). Immigration will potentially increase the rate of acquired valvular disease in high income countries (Siu et al., 2001; Sliwa et al., 2014) and the spectrum of valvular pathology may be under-diagnosed, especially in minority groups such as immigrants (Knight et al., 2019).

A recent Australian population-based study reported that the Indigenous age-standardised RHD prevalence (666.3/100 000) was 61.4 times higher than non-Indigenous (10.9/100 000) individuals (Katzenellenbogen et al., 2020). Further, female RHD prevalence was double that in males, highlighting the ongoing risk of RHD and RHD-complicated pregnancy in this population. The Australian Maternity Outcomes Surveillance System (AMOSS) prospective population study reported 311 confirmed cases of RHD in pregnancy in the 2 years 2013-2014 (4.3/10, 000 women giving birth) (Sullivan et al., 2020). Their results also reflected a higher rate within indigenous populations; of 192 (62%) cases in Australia, 78% were Aboriginal or Torres Strait Islander, and of 119 (38%) cases in New Zealand 90% were Māori or Pasifika (27.2/10,000). Within the Australian Aboriginal population, the rate was highest in the Northern Territory, with a prevalence of 2.22%, which is fifty times higher than the bi-national prevalence, illustrating that the reduced burden of RHD in high-income countries is not consistent and disadvantaged populations remain at risk.

The estimated incidence of mechanical prosthetic heart valves in the UK from 2013 to 2015 was 3.7 per 100,000 pregnancies (Vause et al., 2017). An Australian population study on prosthetic heart valves in pregnancy reported pregnancy rates for women with any prosthetic heart valve (tissue or mechanical) of 11 per 100,000 (Lawley et al., 2014).

Pregnancy associated myocardial infarction

The mechanism for pregnancy associated myocardial infarction (PAMI) is variable depending on specific risk factors and timing of the PAMI, with atherosclerotic changes more common in late pregnancy and arterial dissection increasingly common in the postpartum period. The case series by (Elkayam et al., 2014) reported spontaneous arterial dissection in 43% and atherosclerosis in 27% of cases of PAMI; however, this is a markedly higher rate than other studies and may reflect publication bias within the case series. A spontaneous coronary artery dissection (SCAD) may occur with or without causing an MI and is addressed in the next section, *Pregnancy associated spontaneous coronary artery dissection (PSCAD) 2.3.5*.

While not all studies differentiate the causes of PAMI and rates for pregnancy associated spontaneous coronary artery dissection may be embedded in overall data. It is relevant to note the causes of PAMI because treatment and outcomes vary in important ways dependent on the cause, for example, a stent may be highly effective in cases of atherosclerosis but contraindicated or unhelpful in some SCAD. This detail is not always available in studies or data, for example Balgobin et al. (2020) analysed NIS data from 2003 to 2015 and found that of the 913 PAMI, no cause of MI was determined for 59.4% of patient records.

Table 2.2*: Mechanism of myocardial infarction*

PAMI case or mechanism	Rate	Authors
Coronary atherosclerosis with or without intracoronary thrombus	13-28%	(Balgobin et al., 2020; Elkayam et al., 2014; Satoh et al., 2013)
Intracoronary thrombus without atherosclerosis	8-17%	(Elkayam et al., 2014; Ladner et al., 2005; Satoh et al., 2013)
Pregnancy associated spontaneous coronary artery dissection	15-43%	(Balgobin et al., 2020; Elkayam et al., 2014; James et al., 2006; Ladner et al., 2005; Smilowitz et al., 2018)
Coronary artery spasm (normal arteries)	2-19%	(Ladner et al., 2005; Satoh et al., 2013)
Takotsubo cardiomyopathy	2-2.9%	(Elkayam et al., 2014; Smilowitz et al., 2018)

A systematic review and meta-analysis of PAMI by Gibson et al. (2017) reported a pooled incidence of 3.34 per 100,000 births (2.09-4.58), with the PAMI of individual studies ranging from 0.60 in Sweden (Ros et al., 2001) to 7.60 in the United States (Bateman et al., 2013). The risk of MI in pregnant women is up to 3-4 times higher than in non-pregnant women (Havakuk et al., 2017; James et al., 2006) and PAMI is an important contributor to maternal mortality (McClure et al., 2011).

Smilowitz et al. (2018) and Tripathi et al. (2019) both used the United States NIS database and reported higher PAMI incidence but a lower case-rate mortality than Gibson. Smilowitz et al. (2018) reported a notably higher rate of PAMI in women aged 35 years or older of 23.3 per 100,000 pregnancies, and Tripathi et al. (2019) reported a more than 10-fold increased risk for PAMI in women over 40 years of age as well as a trend of increasing incidence of all cause PAMI of 18.9% from 2005 to 2014.

The increasing incidence is not improving in the USA. Dongarwar et al. (2021) reported an increase in the rates of PAMI from 9.7 per 100,000 hospitalisations in 2009 to 18.1 per 100,000 hospitalisations in 2018, with an average annual percentage change of 7.2%. Analysed by race/ethnicity, there was a marked difference with the rates of PAMI (Hispanic 7.9/100,000, non-Hispanic white 9.3/100,000, and non-Hispanic Black 22.1/100,000) and annual percentage change (Hispanic 12.6%, Non-Hispanic White had no increase, non-Hispanic Black 8.4%).

Vascular dissections: Pregnancy associated spontaneous coronary artery dissection

In non-pregnant women 50 years or younger, 24%-35% of MI are attributable to SCAD (Saw, 2017). In pregnant women SCAD has been suggested to cause up to 43% of myocardial infarctions (Elkayam et al., 2014). While the true prevalence of SCAD is unknown, contemporary series estimated that PSCAD only accounts for less than 5% of SCAD cases (Saw, 2017; Saw et al., 2014; Vijayaraghavan et al., 2014). PSCAD results in a diagnosis of MI in 85.8% to 95.8% of cases (Faden et al., 2016; Havakuk et al., 2017). The data on the incidence and outcomes of PSCAD is even more limited than that for SCAD, and at the time of writing only two PSCAD nationwide reviews (both from the USA) have been published; Faden et al. (2016) reported an incidence of PSCAD of 1.81 per 100,000 pregnancies, and Beyer et al.

(2020) who studied all arterial dissection in pregnancy, reported a similar incidence coronary artery location in 38.2%; 2.0/100,000.

Vascular dissections: aortic dissection

The combined pregnancy associated arterial dissection (coronary, vertebral, aortic and carotid) incidence in the USA is 5.5/100,000, with an incidence of 1.1/100,000 for aortic dissection (Beyer et al., 2020). An earlier American study reported the incidence of AD was 0.55/100,000 for patients during pregnancy and the postpartum period, which was lower than Beyer but significantly higher than the rate of 0.17/100,000 among non-pregnant controls (Kamel et al., 2016). The absolute increase in the risk of aortic dissection or rupture was markedly higher in patients with a documented connective tissue disorder at 4,960.6 per million, compared to those without a connective tissues disorder 4.9 per million (Kamel et al., 2016). The Swedish incidence of AD in pregnancy is reported to be 1.39 per 100,000 compared to 0.06 per 100,000 non-pregnant women (Nasiell & Lindqvist, 2010), comparable to recent data from the USA 1.1/100,000 (Beyer et al., 2020).

Arrhythmias

Rhythm disorders are acquired or genetic conditions that may be exposed or exacerbated by pregnancy. They can be isolated or secondary to other cardiac diseases (e.g., cardiomyopathy) or metabolic condition (e.g., electrolyte imbalance). Transient arrhythmias may be benign however they can also have negative outcomes for mother and foetus (Siu et al., 2001).

The US rate of any arrhythmia in pregnancy is reported to be 68/100,000, including atrial fibrillation (AF) 27/100,000, supraventricular tachycardia (SVT) 22/100,000, ventricular fibrillation (VF) 2/100,000, ventricular tachycardiac (VT) 16/100,000 (Vaidya et al., 2017). The rate of hospitalisation due to arrhythmia increased by 58% from 55/100,000 in 2000 to 83/100,000 in 2012, with the biggest increased seen in AF (111%).

Sustained SVT becomes more frequent during pregnancy, occurring in 22/100,000 pregnancies (Vaidya et al., 2017) and the recurrence rate of existing paroxysmal supraventricular tachycardia (PSVT) in pregnancy is estimated to be 50% (Silversides et al., 2006). Clinically relevant VT during pregnancy occurs in 1.3-1.4% of arrhythmia secondary to

CHD (Ertekin et al., 2016; Salam et al., 2015) and AF has been reported in pregnancy in 2,222/100,000 women with structural heart disease (Chokesuwattanaskul et al., 2019).

Heart failure

Heart failure is most common in older populations and is under-researched in younger cohorts, including pregnant and postpartum women. Mogos et al. (2018) examined the NIS data for 2001-2011 reporting an overall rate of HF of 112/100,000 pregnancy-related hospitalisations for women with and without pre-existing conditions including cardiomyopathy and valvular disorders. About 60% of cases were diagnosed postpartum and there was an increase in diagnoses across the study period, most notably for postpartum diagnoses (7.1% vs 4.9% for antepartum). A Swedish study used three national registries to record heart failure in the last 3 months of pregnancy up to 6 months postpartum from 2007-2010 reporting a lower incidence of 1:5,710 births (17.45/100,000) despite the extended timeframe (Barasa et al., 2017). HF is a common complication of existing cardiac disease. A ROPAC study of pregnant women with valvular heart disease, congenital heart disease, ischaemic heart disease, or cardiomyopathy found HF was the most common complication of pregnancy (13.1%) for women with those conditions (Ruys et al., 2014).

Cardiomyopathies

The most common cardiomyopathies (CMY) in the general population are hypertrophic (HCM) dilated cardiomyopathy (DCM). Rare types are arrhythmogenic right ventricular cardiomyopathy/dysplasia (ARVC/D), restrictive (RCM), Takotsubo and left ventricular non-compaction cardiomyopathies. HCM and ARVC are usually genetic, while DCM and RCM have mixed causes (McKenna et al., 2017). Peripartum cardiomyopathy (PPCM) is idiopathic and is the most common CMY in pregnancy and postpartum, and is discussed below.

Data on the prevalence of HCM and DCM in pregnancy and postpartum is variable, mostly from developed countries, may not discriminate between the type of cardiomyopathy and is based on small cohorts. HCM has a reported incidence in the general population of 1:500; however Australian genetic research estimates the minimal prevalence of HCM gene carriers could be 1 in 200 (Semsarian et al., 2015) .

Peripartum cardiomyopathy

Current diagnostic guidelines for PPCM are left ventricular systolic dysfunction and HF where no other cause of HF is found, occurring in late pregnancy to the first 5 months postpartum, however PPCM can occur at least up to 12 months postpartum (Wu et al., 2017). The LV may not be dilated but the ejection fraction (EF) is usually reduced below 45% (Sliwa et al., 2010). Data on the prevalence of PPCM is inconsistent with studies reporting various timeframes, often not including a minimum of five months postpartum, despite PPCM most commonly occurring postpartum, thus these studies likely underestimate incidence (Masoomi et al., 2018). The incidence of PPCM varies between ethnicities within countries and between countries. National rates in the USA range from 1 in 2,400, to 1 in 4,000 (Sliwa et al., 2010); including white women 1 in 4,075, black women 1 in 1,421, Hispanic women 1 in 9,861, and Asian–Americans 1 in 2,675 deliveries (Arany & Elkayam, 2016; Brar et al., 2007). Incidence is reported elsewhere as 1 in 1,000 in South Africa (Desai et al., 1995), 1 in 3,790 in Taiwan (Wu et al., 2017) and a landmark early study found the incidence in Haiti to be 1 in 300 (Fett et al., 2005). The reported incidence is increasing, and this may reflect either actual increases (in part due to increasing age and increasing multifoetal presentations both being associated with PPCM) and or improved diagnosis (Elkayam, 2011). For example, PPCM incidence in the US increased from 85 in 2004 to 118 per 100,000 live births in 2011 (Kolte et al., 2014).

2.3.2 Maternal outcomes

The challenge of quantifying the prevalence of maternal mortality is amplified when attempting to appraise maternal morbidity attributable to cardiac causes. Maternal morbidity is defined as "*any health condition attributed to and/or complicating pregnancy and childbirth that has a negative impact on the woman's wellbeing and/or functioning*." (Chou et al., 2016 p2) It is critical to understand the scope of maternal outcomes, in both the short- and long-term in order to respond effectively and reduce avoidable morbidity (physical and mental health) and mortality (England et al., 2020). However, to date, most maternal morbidity research focuses on obstetric causes and does not include late postpartum.

Overall maternal mortality

Cardiovascular disease is the single largest cause of indirect maternal mortality accounting for over 33% of pregnancy-related maternal deaths (Ferranti et al., 2016; Knight et al., 2016; Nair et al., 2017). The incidence of maternal death is expressed as the maternal mortality ratio (MMR). The MMR in Australia is calculated using direct, indirect and not classified maternal deaths (excluding coincidental deaths and deaths awaiting classification) and expressed as per 100,000 women giving birth. Maternal deaths in Australia are measured up to 42 days postpartum, and thus do not include all CDPP deaths. In the three years from 2015 to 2017, the total MMR in Australia was reasonably stable with 59 deaths associated with 915,615 births; MMR 6.4/100,000 with 8 deaths due to cardiac causes (0.87/100,000; 13.6%), the second highest cause of death after suicide (18.6%) (Australian Institute of Health and Welfare, 2020b). The United Kingdom Maternal, Newborn and Infant Clinical Outcome Review Programme (MBRRACE-UK) data for the same period 2015-2017 included 209 deaths within 42 days of 2,280,451 women giving birth; MMR 9.2/100,000; of which 48 deaths were cardiac (2.1/100,000, 23%) (Knight et al., 2019). When MBRRACE-UK included deaths up to 365 days postpartum the number of cardiac deaths rose from 42 to 82 (3.6/100,000).

Canadian data for maternal deaths up to 42 days postpartum from 2002 to 2017, includes overall maternal deaths of 9.3/100,000 of which 38.1% were cardiac (3.5/100,000) (Ray et al., 2018) which is lower than an earlier Canadian study that reported maternal mortality with one or more cardiovascular conditions was 4.7/100,000. Of note this was higher than deaths associated with hypertensive disorders (1.6/100,000) and preeclampsia 1/100,000) (Lisonkova et al., 2011). In the US 142 (22.2%) deaths of women who were pregnant or within 1 year since giving birth were due to cardiac causes (8.2/100,000) (Briller et al., 2017). Lower mortality rates were reported in a study of all CDPP deaths up to 1 year postpartum from 2003 to 2013 in the Netherlands 2.4/100,000 (Lameijer et al., 2020). Causes were AD (21%), ischaemic heart disease (IHD, including HF and PAMI) (18%), all cardiomyopathies (21%), unexplained sudden death (28%), valvular disease (8%) and CHD (1%), with 55% of the deaths occurring postpartum. Maternal deaths due to CHD occur in 170 to 192 per 100,000 cases, compared to 2 to 7 per 100,000 in women without CHD (Liu et al., 2022; Thompson et al., 2015). The United Kingdom Obstetric Surveillance System (UKOSS) data on mechanical prosthetic heart valves and pregnancy reported a higher maternal death of 9% (Vause et al., 2017).

Maternal morbidity

CDPP complicates up to 4% of pregnancies (Regitz-Zagrosek et al., 2018) and up to 16% of pregnancies in women with previous cardiac conditions (Silversides et al., 2018). These rates increase when you include women up to 12 months postpartum, however data is less available. A recent systematic review and meta-analysis of the impact of severe maternal morbidity (SMM) on perinatal outcomes in high-income countries found maternal cardiovascular disease is the most frequently cause associated with stillbirth OR 15.24 and perinatal death OR 3.92 (Mengistu et al., 2020).

A 2019 study used the Nationwide Readmissions Databases (2010 to 2014) and reported that 5.2% of HD patients and 1.4% of women without HD were readmitted to hospital (Lima et al., 2019). Major adverse cardiovascular and cerebrovascular events (MACCE) were higher in women with HD compared with women without HD (2.68% vs 0.17%), with greater than 10% readmission at 42 days for women with CMY. A 2017 study used the NIS data from 2003 to 2012 to investigate prevalence, trends and MACE for 81,295 patients with HD in pregnancy (MACEs included a combination of in-hospital death, PAMI, HF, stroke, embolic events, or cardiac complications of anaesthesia) (Lima et al., 2017). CHD was the most frequent type of HD (41.8%), followed by valvular HD (30.9%), all cardiomyopathy (CMY) (20.8%), and pulmonary hypertension (PH) (6.5%). MACE was most frequent in CMY (44.0%) and lowest in CHD (6.2%) which may reflect PPCM (the most frequent type in pregnancy and postpartum) presenting newly diagnosed and often in HF, compared to women with CHD having existing care teams and potentially closely managed pregnancies. The authors noted overall HD prevalence increased in the study period by 24.7% and MACE increased by 18.8% highlighting the growing importance of this issue (Lima et al., 2017).

Congenital heart disease

Women with CHD are more likely to have longer hospitalisation and more cardiac events than women without CHD (14-22 %) (Furenäs et al., 2017; Kirby et al., 2021; Owens et al., 2018; Schlichting et al., 2019; Thompson et al., 2015; Toprak et al., 2021). Women with more severe disease or mWHO classes III or IV, experience more complications than women with less severe disease or mWHO classes I or II, (42.9% vs 7.7%) (Toprak et al., 2021). Arrhythmias, MI, hypertension and HF are the most common adverse cardiac outcomes in pregnancy (Hayward et al., 2017; Thompson et al., 2015; Warrick et al., 2015) and occurred more frequently than for women with CHD than those without CHD (HF aOR 10.03; arrythmia aOR 2.39) (Liu et al., 2022).

A recent New Zealand study noted adverse obstetric outcomes of 42% (Kirby et al., 2021), which is higher than earlier reports of up to 15% for women with CHD (Furenäs et al., 2017; Ntiloudi et al., 2018). Prematurity (birth before 37 weeks gestation) has been reported in 8% to 28% of women with any CHD (Owens et al., 2018; Toprak et al., 2021; van Hagen et al., 2017; Warrick et al., 2015) compared to the overall Australian rate of 7.6% (Australian Institute of Health and Welfare, 2019b). The risk of postpartum haemorrhage may be up to twice as high (Cauldwell et al., 2016), and was recently reported at 26% by Kirby et al. (2021). Miscarriage rates for women with CHD are high compared to the general population, at 11% to 17.8%, (Drenthen et al., 2010; Furenäs et al., 2017). Termination of pregnancy is reported at 5% to 8.5% (Drenthen et al., 2010; Zentner et al., 2016) and combined pregnancy loss (miscarriage and therapeutic termination) for all CHD is as high as 26% (Koerten et al., 2016; Ntiloudi et al., 2018). Women with a higher prediction of neonatal risk are three times as likely to seek termination of pregnancy than women without identified neonatal risks; however accurate information on these risks may not be available, reducing the capacity to make informed decisions (Koerten et al., 2016).

Combined data for CHD can obscure results for individual conditions and risk needs to be assessed for each individual condition and person. For example, a study on pregnancy outcomes for women with a Fontan circulation reported high rates of miscarriage (42.5%), prematurity (70.6%), neonatal death (11%) and a low median birthweight of 1,350gms (Zentner et al., 2016). Uncorrected Eisenmenger syndrome is associated with a very high risk of cardiac events (65.5%), heart failure (48.3%), and maternal mortality (10.3%), representing the severe end of the spectrum of CHD (Sliwa et al., 2020).

Valvular disease and valve replacements

A systematic review and meta-analysis of valvular disease in pregnancy found maternal death for severe and moderate mitral stenosis (MS) of 3% and 1% respectively, severe aortic stenosis (AS) of 2% and no deaths recorded for moderate AS (Ducas et al., 2020). In South Africa, 26% of maternal deaths are due to valvular heart disease (Anthony et al., 2016). An Australian study of 311 women with rheumatic heart disease (RHD) reported two neonatal deaths (6.5/1000 births) and a stillbirth rate of 22.3/1,000 births, with a markedly higher rate in women taking anticoagulation during pregnancy (9.4% versus 1.4%) (Sullivan et al., 2020). Maternal death rates are high in low-income countries, including Nepal 4% (Chhetri et al., 2014), India 1.8-2% (Baghel et al., 2020; Sawhney et al., 2003) and Senegal 34% (Diao et al., 2011). Late diagnosis affects outcomes and is more common in low and middle-income countries, for example, 35% of women had their cardiac condition first diagnosed during pregnancy (Suri et al., 2019) compared to 10% of women in Australia (Sullivan et al., 2020).

Adverse maternal outcomes for mixed valvular conditions (including RHD) are around 14% (Baghel et al., 2020; Silversides et al., 2018), including post-partum haemorrhage (10%) and admission to higher care units (19%) (Sullivan et al., 2020). A systematic review and meta-analysis of pregnant women with severe MS had a risk of pulmonary oedema 37% and new/recurrent arrhythmias 16%, and stillbirth, neonatal death and preterm birth rates were 4%, 2%, and 18% respectively (Ducas et al., 2020). Women with moderate MS had a risk of pulmonary oedema (18%), new/recurrent arrhythmias (5%), stillbirth (2%) and preterm birth (10%). Women with AS have better outcomes with the risk of pulmonary oedema (9%), new/recurrent arrhythmias (4%), and stillbirth, neonatal death and preterm birth rates were 2%, 3% and 14% respectively. No neonatal deaths were reported for women with moderate AS, though they had pulmonary oedema (8%), new/recurrent arrhythmias (2%), and preterm birth (13%).

A ROPAC study of women with valvular heart disease reported obstetric complications in 18% of women (Roos-Hesselink et al., 2019). Compared to women without valvular disease, women in the USA with valvular disease have a higher risk for pre-eclampsia (aOR 1.9), intra-postpartum haemorrhage (aOR1.4), PPCM (aOR 65), pulmonary oedema (aOR 17), acute ischemic heart disease (aOR 19) and arrhythmias (aOR 22) (Minhas et al., 2021).

Women with heart valve prostheses have a pooled estimate of maternal mortality was 1.2%, with a higher rate in the mechanical valves subgroup of 1.8% compared to the bioprosthetic subgroup 0.7%; the thromboembolism rate was 9.3%s (Lawley et al., 2015) which is lower than other estimates of 7% to 23% (Elkayam & Bitar, 2005; Siu et al., 2020). Serious or severe maternal morbidity for women with mechanical prosthetic heart valve is 14.4% to 41%, compared to 1.5% for women without valve prostheses (Siu et al., 2020; Vause et al., 2017). Data for mechanical and tissue prosthetic valves includes pregnancy loss (miscarriage and termination) in up to 20.8% of pregnancies, 5.0% perinatal mortality and maternal thromboembolism in 9.3%; anti-coagulant use or cessation was inconsistently reported across the studies (Lawley et al., 2015). An Australian study on mechanical heart valves reported no maternal deaths, but the risk for an adverse event was higher than the general population, including SMM (13.9% vs. 1.4% of births), major maternal cardiovascular event (4.4% vs. 0.1%), preterm birth (18.3% vs. 6.6%) and miscarriage (15.4% vs. 9.3%) (Lawley et al., 2014).

Pregnancy associated myocardial infarction (PAMI)

PAMI before giving birth is associated with foetal prematurity and mortality, with the risk increasing in relation to the severity of the maternal cardiac disease, while maternal mortality is higher in the peripartum and postpartum periods (Elkayam et al., 2014; Li et al., 2017; Regitz-Zagrosek et al., 2018). Women with IHD had surprisingly good maternal outcomes, with no mortality and 4% heart failure in a ROPAC study; however, the authors cautioned that there is limited evidence in this area (Roos-Hesselink et al., 2019). An earlier meta-analysis found pooled case fatality due to PAMI using a fixed-effect model was 5% (Gibson et al., 2017), which was similar to a recent large US population study that found 4.5% of women died (Balgobin et al., 2020). Tripathi et al. (2019) noted a 40.0% reduction in PAMI mortality in the decade to 2014.

Elkayam et al. (2014) reported ST-segment elevation MI (STEMI) in 75% of PAMI while Smilowitz et al. (2018) reported STEMI in 42.4%; the difference may be explained by the higher rate of PSCAD and the use of published case reports in the Elkayam study compared to the population study by Smilowitz. STEMI is associated with increased myocardial damage and poorer outcomes compared to non-STEMI infarcts.

A contemporary ROPAC study reported 20.5% of women with IHD developed acute coronary syndrome (pre-existing IHD 15.4% vs 100% antenatal onset IHD), and 5.1% developed heart failure (pre-existing 4.8% vs 7.7% antenatal onset) (Baris et al., 2020). Interestingly, women who had undergone revascularization prior to pregnancy did not have fewer events than women who had not undergone the procedure. Additional research of maternal outcomes include heart failure and cardiogenic shock (6.5% to 38%), ventricular arrhythmias (12% to 25.7%), recurrent angina and MI (19%) (Balgobin et al., 2020; Elkayam et al., 2014; Smilowitz et al., 2018), respiratory failure or arrest (20.6%) (Balgobin et al., 2020), pre/eclampsia and gestational hypertension (28.6%), fluid and electrolyte imbalance (22.8%), transfusion (14.8%), postpartum depression (11.0%), postpartum haemorrhage (9.8%) (Tripathi et al., 2019), and acute renal failure (10.1%) (Balgobin et al., 2020). In the US women with PAMI had more than double the obstetric complications than women who did not have PAMI (46.4% vs 20.6%) (Balgobin et al., 2020), and prematurity is three times higher than background levels and are largely iatrogenic (Burchill et al., 2015; Cauldwell et al., 2019).

Pregnancy associated spontaneous coronary artery dissection (PSCAD)

PSCAD is a more extreme phenotype than non-pregnancy associated SCAD (Maas et al., 2019; Tweet et al., 2017). Maternal mortality case fatality rate is estimated at 3.8% for PSCAD without MI and 4.5% with diagnosed MI (Faden et al., 2016; Havakuk et al., 2017). Increased and improved angiography, reduced thrombolysis and increasingly conservative or percutaneous management are associated with marked reductions in maternal (85% in earliest reports to 4% in the last decade) and foetal mortality (50% in earliest reports to 0% in the last decade) and women are less likely to require a cardiac transplant due to cardiomyopathy (Faden et al., 2016; Havakuk et al., 2017 ; Paratz et al., 2018). However, more recent changes in management are associated with a significant improvement in both maternal and foetal mortality (Paratz et al., 2018).

Compared to women with non-PSCAD PAMI, women who have PSCAD are more likely to have a STEMI, ongoing chest pain, new or persistent dissections and require medical intervention, including implantable defibrillator and heart transplantation (Faden et al., 2016; Havakuk et al., 2017; Tweet et al., 2017). Timing of the PSCAD influences maternal and foetal/neonatal outcomes, with PSACD being more common in the postpartum, and thus not affecting neonatal outcomes. A review of PSCAD found that 24% of women experienced cardiogenic shock requiring a high level of intervention; 28% needed ventilation, 28% urgent percutaneous coronary intervention, and 27.5% required urgent coronary artery bypass surgery (Havakuk et al., 2017). In women who have a PSCAD plus MI, complications include heart failure (30.3%), cardiac arrest (13.6%), ventricular fibrillation or flutter (12.1%), haemorrhage from a procedure (10.6%) and blood transfusion (15.6%) (Faden et al., 2016). Women with PSCAD are more likely to have left ventricular function ≤35% when compared with women with non-PSCAD PAMI (26% vs. 10%) (Tweet et al., 2017).

Aortic dissection

Aortic dissection in young women is a rare event with pregnancy a common risk factor. The consequences of AD can be devastating, with higher maternal and foetal mortality rates than other cardiac conditions in pregnancy (Immer et al., 2003; Lansman et al., 2017). Due to the rarity of cases, and the heterogeneity of causes, including some that are relatively newly discovered (such as Loeys–Dietz syndrome which was first described in 2005), most literature is based on case reports, and robust population level epidemiological data is limited (De Martino et al., 2019; Rajagopalan et al., 2014). Morbidity and mortality are influenced by the cause of the dissection (e.g., Marfan syndrome) compared to no known risks, the type of dissection, timing in pregnancy and postpartum, and pregnancy management. Some reports suggest that the incidence of aortic dissection is increasing, and mortality is decreasing in recent years (Banerjee et al., 2015). These changes may reflect actual changes, or greater awareness and better diagnosis may have identified more cases, combined with improved management.

MBRRACE UK and Ireland 2015-2017 reported aortic dissection as the cause of 11% of cardiac deaths in pregnancy (Knight et al., 2019). In the Netherlands the overall maternal mortality rate from cardiovascular disease was 3 per 100,000 deliveries, and nearly half of these were due to aortic dissection with a case fatality rate of 83% (Huisman et al., 2013). International reviews by Silvestri et al. (2019) and De Martino et al. (2019) report maternal mortality as 25% and 23%, and foetal mortality as 6.3% and 27% respectively.

Pregnancy complications may be due to an underlying cause (e.g., connective tissue disorder), aortic dissection or pregnancy itself. Significant complications associated with aortic dissection include miscarriage and recurrent miscarriage, postpartum haemorrhage, increased rates of surgery and caesarean section (Bradley et al., 2014; Murray et al., 2014).

Arrhythmias

Arrhythmias in pregnancy are associated with an increased mortality risk (atrial fibrillation: OR 13.13; supraventricular tachycardia: OR 6.32; ventricular tachycardia: OR 40.89); however, mortality is decreasing with a 24% decrease reduction from 5.7% in 2000 to 3.7% in 2012 (Vaidya et al., 2017).

Pregnancy-related hospitalisations with any arrhythmia had higher rates of and maternal or foetal complications (36.5%) compared with all women (0% and 21.8%, respectively) (Vaidya et al., 2017). Heart failure during pregnancy is twice as common in women with ventricular tachyarrhythmia (VTA) than those without (24% vs 12%) (Ertekin et al., 2016). Overall adverse maternal outcomes include severe maternal morbidity, caesarean section, HF, and pre-eclampsia (Chang et al., 2017; Chokesuwattanaskul et al., 2019; Ertekin et al., 2016).

Heart failure and cardiomyopathies

Data for HF often includes a composite of types, including PPCM which is the most common form of HF in pregnancy. Mogos et al. (2018) report that 9% of all in-hospital pregnancy death is due to HF, with an annual increase of 9.8% during their study period 2001 to 2011. Birth-related HF was associated with the highest risk, followed by antenatal and postpartum HF (aOR 31.9, aOR 15.9, and aOR 4.0 respectively).

A contemporary systematic review of 50 studies of MACE events in women with mixed CMY (ischaemic CMY 4%, PPCM 28%, non-ischaemic CMY 68%) found a large heterogeneity of reported results, with ventricular arrhythmia and death the only two MACE events reported consistently (VT/VF 15% to 19%, maternal death 2% to 6%) (Dodeja et al., 2021). Billebeau et al. (2018) studied pregnancy outcomes for women with DCM, HCM, ARVC or left ventricular non-compaction CMY from 1997 to 2013. Findings included that there was a dearth of available data, which the authors suggest accounts for widely varying rates of published results of adverse maternal cardiovascular events, for example ranging from 0% to 73% in women with HCM. Fewer data are available on DCM or ARVC. Billebeau et al. (2018) reported major cardiovascular events during 35% of pregnancies, including three cardiac deaths, 5% intrauterine foetal deaths, and 23% premature births. These results differ to Gandjbakhch et al. (2018) who reported no deaths or heart failure and only 2 preterm births in 60 pregnancies in 23 women with ARVC/D from 1968 to 2016. A recent Canadian case series of nine women reported no maternal deaths with only one woman having a pregnancy and postpartum complicated by arrythmia (Luo et al., 2022). An earlier study that used combined data of the Johns Hopkins and the Dutch ARVD/C registry, identified 26 women affected with ARVD/C during 39 singleton pregnancies (Hodes et al., 2016). The majority of pregnancies were well tolerated, with 13% complicated by ventricular arrhythmia and 5% by HF with 2 women having an implantable cardiac defibrillator (ICD) implanted during pregnancy.

A 15-year nationwide study in China compared outcomes for DCM in pregnancy with PPCM during birth admission and 1- and 3-year follow up and reported worse outcomes for DCM: all-cause mortality 14.1% vs. 8.4%, MACE 16.4% vs. 7.9%, and 3-year all-cause mortality 19.7% vs. 10.7% respectively (Lu et al., 2017). In a retrospective study of 35 pregnancies in 30 women with DCM (NYHA class I or II prior to pregnancy) 43% births were preterm and 23% of pregnancies were complicated with a cardiac event, and one pregnancy was terminated due to worsening cardiac status, with the authors noting in this cohort pregnancy was well tolerated except the high preterm birth rate (Yokouchi-Konishi et al., 2021).

Twenty three percent of women with HCM experience one or more adverse cardiac events; 15% had heart failure, 12% had arrhythmia and 56% had caesarean births (Goland et al., 2017). Obstetric outcomes included: 3.3% stillbirth, 24.6% premature births, 16.1% small for gestational age (SGA) and 11.1% low Apgar score. Other studies found adverse maternal events occur in up to 14.8% (Ersbøll et al., 2017; Kolte et al., 2014) and 48% (Tanaka et al., 2014), including cardiogenic shock which increased from 1.0% in 2004 to 4.0% in 2011 (Kolte et al., 2014).

Peripartum cardiomyopathy

In a study of 739 women from 44 countries in Europe (33%), Africa (29%), Asia-Pacific (15%), and the Middle East (22%) six-month mortality due to PPCM was 6% overall with regional variations in presentation and outcomes (Sliwa et al., 2020). Maternal death was highest in the Middle East (10%) and lowest in Europe (4%). At diagnosis, 67% of patients had severe (NYHA III/IV) symptoms and 67% had a left ventricular ejection fraction (LVEF) ≤35%. A retrospective cohort analysis of 3,800 patients with PPCM using the Healthcare Cost and Utilization Project 2013 National Readmissions Database reported mortality within 30 days of discharge from birth admission of 1.6% (Chhabra et al., 2017). Earlier studies reported in-hospital maternal mortality due to PPCM of between 1.0% and 3.3%, (Ersbøll et al., 2017; Kao et al., 2013; Kolte et al., 2014; Lee et al., 2018) compared to mothers without PPCM (0.01%) (Lee et al., 2018). This contrasts to 18.7% of women with PPCM dying over a 17 months follow-up in Nigeria (Karaye et al., 2020).

Adverse maternal events occur in up to 18% of PPCM, (Ersbøll et al., 2017; Kolte et al., 2014) including cardiogenic shock which increased from 1.0% in 2004 to 4.0% in 2011 (Kolte et al., 2014). Re-admission for any reason is 10% to 15.1% (Chhabra et al., 2017; Sliwa et al., 2020). Myocardial recovery to greater than 50% LVEF occurred in only 46% of 739 women in an international study that included 49 countries [in Europe (33%), Africa (29%), Asia-Pacific (15%), and the Middle East (22%)] (Sliwa et al., 2020) which is still higher than 22.6% in Nigeria (Karaye et al., 2020), and reflects regional differences. Between 1987 and 2010 in the USA, PPCM was the fourth most common indication for heart transplant in women (all causes, including non-pregnancy-related, idiopathic CMY [44.8%], ischemic DCM [17.1%], and coronary artery disease [9.5%]) (Rasmusson et al., 2012).

2.3.3 Pregnancy in women with heart transplants, implantable cardiac devices and chemotherapy-induced heart failure

While not the focus of this literature review, it is worth noting that improved survival of childhood and pre-pregnancy cardiac disease and other conditions such as cancer means women are increasingly embarking on pregnancy following heart transplantation, implantation of an implantable cardiac defibrillators (ICD) or left ventricular assist device (LVAD), or treatment with cytotoxic therapies.

Heart transplant

Pregnancy after heart transplant involves cardiac health and possibly immunosuppressive treatment, but can be successfully managed (DeFilippis et al., 2021). The maternal and foetal outcomes of pregnancy in the Transplant Pregnancy Registry International of 157 pregnancies in 91 women with heart transplants, complications included hypertension of pregnancy (46%), pre-eclampsia (23%), infections (14%) and rejection during pregnancy (9%) or in the first 3 months postpartum (7%) (Punnoose et al., 2020). Livebirths occurred in 69% of pregnancies, with no neonatal deaths, 41% preterm birth 41% and 37% low birth weight. While pregnancy may be managed, it is worth noting that longer-term mortality remains high; at the most recent follow-up of the 91 women, 30 women had died, an average of 9.4 ± 6.2 years after pregnancy, most commonly due to allograft vasculopathy and rejection (Punnoose et al., 2020).

A 2020 systematic review and meta-analysis included 12 studies on 385 pregnancies in 272 thoracic (heart and lung) transplant recipients including 220 pregnancies in 140 heart transplant patients (Acuna et al., 2020). Outcomes indicated low mortality during pregnancy or the first year postpartum (pooled risk 0.1%) but a significant risk of pregnancy morbidity and a markedly increased risk (pooled risk 15.4%) of mortality during follow up of 3-7 years. An Australian case series of five pregnancies in three recipients of heart transplant reported no deaths and that multidisciplinary management was required and longer-term outcomes are yet to be realised (Boyle et al., 2021).

Cardiac surgery

Cardiac surgery during pregnancy involving cardiopulmonary bypass (CPD) is associated with maternal mortality of 11.2%, pregnancy loss of 33.1%, maternal morbidity 8.8% and neonatal complications in 11.8% (Jha et al., 2018). Eighty-nine percent of procedures were emergent and most were performed during the 2nd trimester with valvular disease the three most common indications (mitral stenosis 29%, prosthetic valve dysfunction 26%, and aortic stenosis 13%).

Ventricular assist devices

Ventricular assist devices (VAD) can be for short-term use, such as recovering from cardiac injury or MI, or longer-term use, typically for ongoing management of heart failure, or as a ‘bridge to transplant’. The left VAD (LVAD) is the most common device, and in women who are pregnant or postpartum LVADs may be inserted to manage current HF or PPCM, or women may embark on pregnancy with an LVAD already insitu. Current data for women who embark on pregnancy with a VAD is limited to case reviews. A 2021 systematic review yielding 6 articles and a total of 6 cases reported pregnancy as complex but tolerated by 5 women, with one maternal and neonatal death (Meece et al., 2021). Two subsequent case studies similarly remark on case complexity but no SMM or MACE and reiterate the requirement for close multidisciplinary management and monitoring (A. Malik et al., 2021; Yadalam et al., 2022). Further, in the absence of long-term data on outcomes from pregnancy with a LVAD counselling is critical, in particular the documented 20%-50% risk of right ventricle failure following LVAD implantation in general LVAD population (Argiriou et al., 2014), and a one-year survival of less than 50% if biventricular support is required (Frankfurter et al., 2020).

Implantable cardiac defibrillator (ICD)

The number of patients of reproductive age receiving ICDs is increasing (Topf et al., 2021). Currently there is limited data on maternal and infant outcomes for women with ICDs, though overall the outcomes do not appear markedly different to the general population, and are likely to be associated with the cardiac pathology that led to the requirement of an ICD, rather than the ICD itself (Topf et al., 2021). Women with advanced CMY or HF or rhythm disorders such as Long QT Syndrome may have ICDs prior to pregnancy or implanted during pregnancy and postpartum, and there is limited data in this cohort. One study of 20 pregnancies between 2006 and 2013 in 12 women with ICDs due to structural cardiomyopathies or channelopathies (including Long QT Syndrome) found no adverse effects of having an ICD on maternal and infant outcomes, except possibly one miscarriage at four weeks gestation which occurred shortly after the mother experienced ICD discharge/shocks (Boulé et al., 2014). There were four miscarriages in total, one stillbirth and one termination of pregnancy and the live birth rate was 70% (14/20). Further, pregnancy was not thought to interfere with the ICD function. An earlier study involved 19 pregnancies in 14 women with CHD, CMY, Long QT syndrome, and idiopathic cardiac arrest (Schuler et al., 2012); the live birth rate was 95% (18/19), with one abortion before 24 weeks. In this study there were no reports of inappropriate shocks (ICD discharging) and pregnancy was generally well tolerated, however, medical and device complications were present.

Chemotherapy-induced heart failure

Improvements in cancer outcomes means more women of reproductive age may have chemotherapy-induced left ventricular dysfunction and HF, or it may be revealed with the increased cardiac demands of pregnancy. In Australia, more than 4,000 women aged 20-39 years are diagnosed with cancer annually (Australian Institute of Health and Welfare, 2021b), with more women diagnosed as children now considering pregnancy. A 2020 meta-analysis including 6 studies of 2,106 pregnancies of cancer survivors (predominantly childhood cancer survivors) found the total weighted incidence of LV dysfunction or heart failure in women was low (1.7%) (Nolan et al., 2020). However, women with a history of cancer treatment-related cardiac dysfunction had a significantly higher incidence of left ventricular dysfunction or HF during pregnancy or within 12 months after delivery compared with those without this history (28.4% versus 0.24%; OR 47.4).

2.3.4 Subsequent pregnancies following SCAD, PSCAD or PPCM

There has been little research on the risks and outcomes of future pregnancies for women who have had CDPP, or for women who have had a SCAD not in pregnancy to have a subsequent pregnancy. A study of 23 women who had 32 pregnancies following a SCAD found no increased risk exposure to recurrent SCAD compared with matched controls, with overall risk of recurrence at 5 years of 14.8% (Tweet et al., 2020). Whilst this is promising for women wishing to extend their family, the authors note the small size of the study and the physiological changes of pregnancy remain a concern when considering post-SCAD pregnancy.

A study reported on 34 women from Germany, Scotland and South Africa who had a pregnancy subsequent to PPCM (Hilfiker-Kleiner et al., 2017). Key findings include: an overall relapse rate of 56% (defined as <50% LVEF or death after at least 6-month follow-up), 12% (4/34) mortality, and worse outcomes for women who entered their subsequent pregnancy with persistently lowered LVEF (<50% EF), the majority of whom were of African ethnicity (53%) indicating worse outcomes compared to the women from Germany and Scotland. Outcomes were not affected by parity, twin pregnancy, gestational hypertension or smoking.

2.3.5 Long-term cardiac outcomes

In recent years there has been an increase in research of CDPP and progress in the short-term management of pregnancy complications, however the long-term outcomes of complicated pregnancies are currently under-researched and largely underestimated (Regitz-Zagrosek, 2019). Given the established increased risk of premature and more severe cardio- and cerebrovascular disorders in women with pregnancies complicated by hypertension (chronic and gestational) and preeclampsia, it is essential to quantify long-term outcomes for women with CDPP and risks to better inform pregnancy counselling and management (Arnott et al., 2019; Garovic et al., 2020).

One recent study of long-term cardiovascular outcomes following pregnancy provided a unique insight into the potential sequalae for mothers (Siu et al., 2021). Women with pre-existing cardiac disease and a comparison group of women without pre-existing cardiac disease were followed for 20 years, with primary outcomes of a composite of mortality, arrhythmia, atrial fibrillation, stroke, myocardial infarction, and secondary outcomes including cardiac procedures, hypertension and diabetes mellitus. At 20-years 33.1% of the women with cardiac disease had the primary outcome compared to 2.1% of the women without cardiac disease (aHR 19.6), 31% had a cardiac procedure. Women with pre-existing cardiac disease were also more likely to have the composite secondary outcome (aHR 1.6). The majority of women were classified as low risk using the CARPEG II criteria (71.5%) and mWHO (70.2%) risk tools, highlighting that long-term sequalae occurs across the risk spectrum, though clearly women with high-risk scores had poorer outcomes (adjusted cumulative risk in WHO Class IV and V categories was 52.8% to 54.2% compared to 12.5% for women with WHO Class I). Of the women with cardiac disease, those who had a pregnancy complication had increased risk of primary or secondary outcomes compared to women who did not (48.5% vs 32.5%). Nearly half of the women with cardiac disease had additional births and there was no significant relationship between the number of births and primary outcome, a new finding that can inform decisions about family planning.

2.3.6 Neonatal outcomes

This thesis does not focus on neonatal outcomes but they are briefly mentioned here as a relevant aspect of maternal outcomes. Neonatal death is seen in 0.6% to 2.3% of births to women with CHD and combined stillbirth and neonatal deaths range from 1.1% to 4% (Drenthen et al., 2010; Furenäs et al., 2017; Roos-Hesselink et al., 2013). Neonatal adverse events are reported in 11.2% to 15.3% of births to women with CHD (Furenäs et al., 2017; Owens et al., 2018; Warrick et al., 2015). Neonates have a lower birthweight than offspring of women without CHD (Caruana et al., 2017; Roos-Hesselink et al., 2013) and in low resource countries up to 56% of neonates weighed less than 2500g (Arora et al., 2015). Small for gestational age (SGA) ranges from 5% to 65% (Drenthen et al., 2010; Hayward et al., 2017; Hrycyk et al., 2016; Kirby et al., 2021; Owens et al., 2018; van Hagen et al., 2017). Offspring of women with CHD have an increased rate of congenital anomalies overall (congenital anomalies/malformations 7.4% versus 2.4%) (Caruana et al., 2017) and rates of congenital heart disease are 2.9% to 7.0% (Furenäs et al., 2017; Owens et al., 2018).

An observational retrospective cohort study from Tunisia of pregnant women with severe valvular disease who gave birth between 2010 and 2017 noted neonatal complications in 39.3% (Hammami et al., 2021). Infant outcomes in Australian maternal RHD are 20% prematurity including nine (3%) extremely preterm (< 28 weeks), 19% low birthweight, 15% small for gestational age and one-third required admission to special/neonatal intensive care with Aboriginal and Torres Strait Islander babies being most likely to receive higher care (43%) (Sullivan et al., 2020). Maternal prosthetic valves are associated with poor foetal outcomes in 20% to 47% of pregnancies (Roos-Hesselink et al., 2019; Vause et al., 2017).

Pregnancies in women with IHD are associated with high rates of preterm birth; 20.2% in pre-existing IHD and 38.5% in pregnancy-onset IHD (Baris et al., 2020). Perinatal deaths in PAMI of 4% to 5% are related to maternal outcomes, including maternal surgery and death (Cauldwell et al., 2019; Elkayam et al., 2014). PSCAD foetal death has been estimated at 2.5% (Havakuk et al., 2017). Neonatal outcomes apply to antepartum PAMI and PSCAD and relate to premature delivery and urgent cardiac surgery (Havakuk et al., 2017). Maternal aortic dissection is associated with prematurity, premature rupture of membranes and SGA (Bradley et al., 2014; Braverman et al., 2021; Russo et al., 2022).

A meta-analysis of AF in pregnancy found a pooled estimated incidence of foetal events of 26.6% (Chokesuwattanaskul et al., 2019). Foetal and neonatal outcomes include low birthweight, foetal stress, and foetal abnormalities (Chang et al., 2017), premature birth, intrauterine growth restriction, small for gestational age, respiratory distress syndrome, intraventricular haemorrhage, death (Chokesuwattanaskul et al., 2019; Ertekin et al., 2016; Henry et al., 2016). Billebeau et al. (2018) reported 60% of pregnancies in women with HF were complicated by one or more foetal or neonatal adverse events, most frequently low birthweight (40%) and hypoglycaemia (26%). HF is also associated with neonatal death and lower APGAR scores appearance, pulse, grimace/reflex, activity/tone and respiration) than non-HF patients (Ng et al., 2018). Data on neonatal outcomes for PPCM is limited as PPCM often presents postpartum. A EURObservational Research Programme paper reported a neonatal death rate of 3.1% (Sliwa et al., 2017). Other neonatal outcomes include 30.3% prematurity, 27.3% small for gestational age and 6% congenital cardiovascular malformation (Ersbøll et al., 2017).

Part B: The lived experience of having cardiac disease in pregnancy and the first twelve months postpartum

2.3.7 Results

There is a lack of comprehensive data on the experiences of women with CDPP. Limited studies review the impact on activities of daily life, mental health, quality of life (QoL), relationships, career and finances, and the persistent risk of worsening of their cardiac health and potentially premature mortality.

Health and healthcare experiences

At the time of writing one systematic review and meta-analysis on women's experiences with cardiac disease and pregnancy has been conducted (Dawson et al., 2018). With broad search terms only 11 papers were identified as appropriate and included in the review, and of these five were explicitly about experiences of CDPP while the others included fertility and pregnancy in a broader discussion, underscoring the paucity of research in this area. Key thematic categories identified were identity and control, self-care and risk awareness in pregnancy, social support for decision-making, and healthcare experiences, and the authors highlight the need for greater engagement with women and the development of models of care that are responsive to women's needs, knowledge and desired outcomes.

In studies on the experience of being diagnosed with a cardiac condition during pregnancy or postpartum women describe losing trust in the health system after having their symptoms dismissed by health care providers and of incorrect initial diagnoses, including "new mum anxiety", when physical symptoms are misinterpreted as psychiatric symptoms (de Wolff et al., 2018; Dekker et al., 2016; Patel et al., 2016). The studies are summarised in *Table 2.3*. It is fraught to try to separate individual aspects or themes of experience as they are intimately related. Nonetheless, the central issues considered are mental health, reproduction and mothering, and quality of life.

Table 2.3: *Health and healthcare experiences*

Author, year	Method	Aim	Findings
Healthcare or health experiences with CDPP			
Dawson et al., 2018	Systematic review and meta-synthesis	• To synthesise qualitative data on the experiences of women with CDPP to improve quality of cardiac care	• Women had variable healthcare experiences. Key themes were challenges with autonomy and control, lack of practitioner knowledge, risk awareness and self-care and the need for specific social support.
Patel et al., 2016	Qualitative: semi-structured interviews	• To explore women's experiences of health care with peripartum cardiomyopathy	• The main theme was 'Exacerbated Suffering', with sub-themes of 'not being cared about', 'not being cared for' and 'not feeling secure.' • Women felt alone and distressed; they felt dismissed and that midwives lacked knowledge of PPCM which led to distrust and dissatisfaction.
Dekker et al., 2016	Qualitative: analysis of posts on online PPCM support groups	• To describe women's experiences being diagnosed with PPCM	• Nearly 40% of women experienced symptom dismissal by HCPs and a quarter were initially given inaccurate diagnoses. • The reaction to diagnosis was feeling devastated and feeling a sense of doom, and women struggled with caring for their baby and the advice to have no further pregnancies.
Hess & Weinland, 2012	Mixed methods: analysis of posts on an online PPCM support group	• To describe the contents of postings made on an online PPCM support group	• Women's main stressors were misdiagnosis and advice to avoid subsequent pregnancies. • Six themes were identified: symptomology, exchange of advice,

			interactions with HCPs, subsequent pregnancies, spirituality, and recovery from heart failure.

Mental health

Table 2.4 outlines the studies examining the mental health outcomes for women with CDPP, all of which involve CDPP. Additional relevant research is discussed below.

Table 2.4*: Mental health and CDPP*

Author, year	Method	Aim	Findings
Mental health and CDPP			
de Wolff et al., 2018	Qualitative: in-depth semi-structured interviews	• To explore women's' experiences of psychological adaptation after severe peripartum morbidity	• The overarching theme was recovering to a new normal after PPCM. • Subthemes were losing trust after not being heard, adjusting from ICU to home, disrupted mothering, having decisions made for them and being able to draw on their inner resources. Additionally, mental health needs were not met.
Donnenwirth et al., 2020	Cross-sectional, correlational survey	• To examine relationships among post-traumatic stress (PTS), depression, and QoL in women with PPCM.	• All participants were positive for depression and PTS correlated significantly and positively with depression. • PTS and depression correlated significantly and inversely with QoL; women with lower education scored higher on PTS and depression, and women who were unemployed or disabled had a lower QoL.
Pfeffer et al., 2020	Mixed methods: clinical interviews and analysis of biomarkers	• To examine the incidence of mental disorders in PPCM, and analyse potential alterations of depression-associated biomarkers	• Major mental disorders were diagnosed in 65% of the PPCM cohort, and compared to controls women with PPCM had altered biomarkers. • The prevalence for major depressive disorders was 4-fold, PTSD 14-fold, and panic disorder 6-fold higher in PPCM patients compared with postpartum women without PPCM.
Rosman et al., 2017	Cohort study: questionnaires on depression and health behaviours	• To characterise the prevalence of depression and health behaviours in PPCM patients	• Nearly 1 in 3 had symptoms of clinical depression which was associated with additional medical conditions. • Depressed PPCM patients were significantly less likely to attend medical appointments than non-depressed women.
Rosman et al., 2019	Quantitative: online mental	• To examine psychological distress and QoL in	• 53% of patients with PPCM scored positive for generalised anxiety and composite cardiac anxiety scores were

	health and QoL questionnaire	patients with PPCM and evaluate changes over time since diagnosis	elevated in the overall sample; cardiac avoidance was significantly higher in newly diagnosed women. • PPCM–specific QoL concerns were prevalent, with no significant group differences.

The experience of being diagnosed is associated with feeling terrified, devastated and at times, a sense of doom (de Wolff et al., 2018, Dekker et al., 2016). Women of reproductive age with cardiac disease report feeling stress, having challenges in taking control and making decisions (low self-mastery) and experiencing a lack of autonomy, (de Wolff et al., 2018; Hess & Weinland, 2012; Hess et al., 2010). The importance of social support is highlighted by women (Dawson et al., 2018). These characteristics are also predictors of poor perinatal mental health reflecting an increased risk for women with CDPP (Akiki et al., 2016).

A study by Liang et al. (2014) found that women who experienced PSCAD had higher mean Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder 7-item (GAD-7) scale scores for anxiety and depression than men and women who had SCAD: PHQ 6.7 vs. 3.7 and GAD-7 8.1 vs. 4.3. A recent study on PPCM found that 26 of 40 (65%) participants had major mental health disorders diagnosed (Pfeffer et al., 2020). Pfeffer et al. (2020) compared to postpartum women without PPCM, the prevalence of major depressive disorders was 4-fold, for post-traumatic stress disorder 14-fold, and for panic disorder 6-fold. Donnenwirth et al. (2020) conducted a cross-sectional, correlational survey study with 28 women with PPCM (mean 3.6 years since diagnosis with PPCM) and reported that all participants measured positive for depression, and that PTSD and depression correlated significantly and inversely with QoL. Of note, Koutrolou-Sotiropoulou, Lima, and Stergiopoulos found that more than half of women with PPCM did not return to premorbid levels of emotional health after one year despite 68% having recovered cardiac function, highlighting the persistent emotional toll of CDPP on young mothers (Koutrolou-Sotiropoulou et al., 2016). Donnenwirth et al. (2020)

Mental health conditions, cardiac disease, and pregnancy and postpartum are closely interrelated, making it appropriate to consider related literature on perinatal mental health in general, and mental health and younger women, such as those who experiences CDPP. A systematic review and meta-analysis estimated the prevalence of postpartum depression among healthy mothers without a prior history of depression who gave birth to healthy infants to be 12%, with an overall prevalence of depression of 17% among mothers (Shorey et al., 2018). This is similar to an earlier systematic review which estimated perinatal depression to be 11.1% (Woody et al., 2017). A Canadian study reported anxiety in pregnancy and early postpartum period to be 15.8% and 17.1% respectively (Fairbrother et al., 2016), with anxiety in pregnancy 5.17 to 6.58 times greater for women with medically complicated pregnancies (Fairbrother et al., 2017). A systematic review of perinatal anxiety estimated prevalence to be 2% to 39% (Leach et al., 2017) and meta-analysis found an estimated 20.7% of perinatal women have one or more anxiety disorders and 1.1% have PTSD (Fawcett et al., 2019).

Younger women appear to be more exposed to the risk of reduced mental health (Liang et al., 2014) and some cardiac conditions have higher rates of associated mental health issues (Johnson et al., 2020; Liang et al., 2014). The bi-directionality of mental health and cardiac disease means anxiety, depression and PTSD, as well as other mental health conditions, are associated with lower attendance at medical follow-up visits, poorer cardiac outcomes, more recurrent cardiac events and higher mortality (O'Neil et al., 2021; Rosman et al., 2019; Smaardijk et al., 2019).

Reproduction and mothering

Table 2.5 *Reproduction and mothering with CDPP*

Author, year	Method	Aim	Findings
Reproduction and mothering with CDPP			
Cauldwell et al., 2017	Retrospective cohort study	• To assess if preconception counselling was offered and used by women with high grade cardiac disease, and compare accuracy of cardiac tools in predicting risk	• Preconception counselling was attended in a little over half of pregnancies; both maternal and foetal adverse events were common. • Cardiac tools varied in accuracy and the best prediction of adverse outcomes was a composite risk score.
Kaemmerer et al., 2012	Clinical assessment and questionnaire	• To report on current sources of information on sexuality, pregnancy and contraception for women CHD.	• Information sources varied between the different age groups, with treating physician and friends the main information sources. • The women rated their level of information regarding sexuality with a median of 3.5 (out of 10), and a median of 5 regarding contraception

			and pregnancy, highlighting inadequate counselling practice.
Ngu et al., 2014a	Mixed methods: Questionnaire, semi-structured interview, medical records and clinical status review	• To understand the motivations and perceptions of women with low-risk and high-risk CHD to have children	• Women had similar motivations to have children regardless of risk status. • Their perceptions of the risk at times appeared unrealistic, and was surpassed by the desire for children.
Ngu et al., 2014b	Mixed method: survey and medical records review	• To assess women's perceptions of their CHD severity and implications in pregnancy, and to compare motivations to conceive to women without CHD	• Women with CHD were concerned about the health risks associated with their CHD; however, half downplayed the seriousness of their CHD. • The motivation to conceive was similar in women with and without CHD.

There are limited studies on reproduction and CDPP, and at the time of writing, none about the experience of mothering with CDPP; *Table 2.5* summarises current literature. Some studies have examined reproductive choices and motherhood for women with an acute illness, severe maternal morbidity, near-miss, or chronic illness (de Wolff et al., 2018; Dorgan et al., 2013; McCoyd et al., 2018; Power et al., 2015; Vallido et al., 2010); however, with increasing prevalence of chronic illness and CDPP in particular (Lima et al., 2017), this work is essential to improve outcomes for women and their children, and to address rising health costs (Admon et al., 2018).

There has been a small amount of research focusing on issues concerning risks and decision-making for family planning (Cauldwell et al., 2017; Ngu et al., 2014a, 2014b), including research on contraceptive choices and use, and unplanned pregnancies (Cauldwell et al., 2017; Holton et al., 2018; Kaemmerer et al., 2012). Women with cardiac disease have similar desires to have families as women without cardiac disease and may underestimate the risk associated with pregnancy and giving birth. The benefits and risks of different contraception choices may not have a robust evidence-base due to a small number of studies and low numbers of participants.

A diagnosis of cardiac disease in pregnancy or postpartum may be completely unexpected. Being unwell with cardiac disease impacts a woman's ability to care for her newborn or return to normal activities of daily life, leading to additional distress (de Wolff et al., 2018; Dekker et al., 2016). Some women are advised to cease breastfeeding or to have no further pregnancies, and this can be devastating (Dekker et al., 2016). Women may experience difficulty making decisions and having others making decisions for them (de Wolff et al., 2018; Hess & Weinland, 2012; Hess et al., 2010).

The physical effects of CDPP can affect how and when a woman gives birth, her recovery from birth, the health of her baby and how she is able to mother her baby. Mothers with serious maternal morbidity or maternal near-miss events and an initial separation from their newborn experience distress, delayed or impaired infant bonding, challenges establishing breastfeeding and required additional support (Hinton et al., 2015a, 2015b; McCoyd et al., 2018). Traumatic birth experiences also impact on a woman's experience of motherhood and her initial relationship with her baby, with women reporting lost bonding time, feelings of failure and the emotional impact of 'relinquishing care of the infant' (de Wolff et al., 2018; Dekker et al., 2016; Elmir et al., 2010).

Women struggle to relinquish care even when acutely unwell, and the importance of their role as mother is not always fully appreciated or facilitated by health professionals (Power et al., 2015). The difficulties of being a new mother in critical care are highlighted by Hinton et al. (2015a) including the anguish women felt being separated from their baby and how important breast feeding was for them, as well as the need for more support. Further, women face challenges managing their acute and ongoing chronic health condition while simultaneously mothering their infant and young children (de Wolff et al., 2018; Power et al., 2015; Rosman et al., 2019; White et al., 2009).

Quality of life

There is also limited research on women's experiences and QoL outcomes for CDPP. Patient reported outcomes (PROs) are essential in understanding and improving clinical and broader QoL outcomes and are integral to person-centred care and shared decision-making (Rumsfeld et al., 2013). *Table 2.6* provides a summary of the relevant research.

Table 2.6 *Quality of life with CDPP and patient-reported outcomes*

Author, year	Method	Aim	Findings
Quality of life with CDPP			
Koutrolou-Sotiropolou et al., 2016	Qualitative: survey	• To determine the impact of PPCM on quality of life and emotional well-being	• Nearly half never returned to their baseline level of activity; 28% discontinued work due to PPCM; 56% never returned to their baseline emotionally after diagnosis. • Most were slightly or not limited by heart failure symptoms, though and 73% were dissatisfied with their current level of symptoms and 67% felt discouraged frequently due to heart failure. • A quarter were satisfied with the counselling they received from their providers.
Patient-reported outcome measures and CDPP			
Hall & D'Souza, 2020	Qualitative: interviews with pregnant women with heart disease, family members, and HCPs.	• To elicit desired research outcomes from pregnant women with CDPP, their family and HCPs to aid development of a core outcome set for studies on cardiac disease in pregnancy (COSCarP), and future research	• Patients and family identified 17 outcomes, mostly related to general health of the baby, congenital anomalies, mental health, and health care delivery. • HCPs identified 45 outcomes which were mostly clinical. • While clinical outcomes are the main focus of published research in CDPP, patients and HCPs emphasize the importance of outcomes related to general maternal and foetal well-being and life impact.

A systematic review of research on cardiac disease in pregnancy found 94% of included studies reported on clinical outcomes or adverse effects only, and none included PROs on life impact and functioning (Hall & D'Souza, 2020). Pregnant women with cardiac disease however want QoL and mental health included as PROs and these should be incorporate alongside the more clinically based outcomes, and employ CDPP-appropriate patient reported outcome measures (PROMs) (Hall & D'Souza, 2020; Parsonage et al., 2020).

Patient-reported anxiety, depression, perceived health, QoL and distress are independent predictors of subsequent hospital readmission and costs, morbidity and mortality. Knowledge of these predictors can help risk assessment and resource development and allocation (Rumsfeld et al., 2013; Vámosi et al., 2020). Disease-specific patient-reported outcome measures instruments are optimal (Algurén et al., 2020), and while there are multiple tools available for various cardiac diseases (Eifert et al., 2000; Thompson et al., 2016), and for pregnancy and postpartum (Mogos et al., 2013), at present there are no validated PROMs specific to individual cardiac diseases in pregnancy and postpartum, though a few studies have adapted existing tools (Koutrolou-Sotiropoulou et al., 2016).

A study on PPCM reported that the participants had a variety of complex cardiac and QoL issues that were not usually seen in heart failure clinics, and these issues are not included in general heart failure PROMs (Rosman et al., 2019). Issues relating to mothering infants and small children were unique to pregnancy-related heart failure (in this case PPCM). Further, the participants parenting role negatively affected nearly all aspects of medical adherence, such as ability to follow-up prescribed diets, exercise, rehabilitation, attendance at appointments and taking medication as prescribed (Rosman et al., 2019).

The outcomes of CDPP are not limited to the acute cardiac event or pregnancy, but persist throughout the woman's life. The limited available literature reports a pervasive and enduring lower quality of life and poorer mental health for women with CDPP, including generalised and cardiac specific anxiety and quality of life concerns that persisted up to 10 years (Koutrolou-Sotiropoulou et al., 2016).

2.4 Literature review discussion

2.4.1 Part A: Cardiac disease in pregnancy and the first twelve months postpartum

The heterogeneity of CDPP and methodological challenges in accurately estimating incidence and prevalence has resulted in a lack of robust epidemiological data internationally. At the time of writing the only Australian data on incidence, prevalence and outcomes of CDPP are three studies; one each on RHD (Sullivan et al., 2020), prosthetic heart valves (Lawley et al., 2014) and Fontan circulation (Zentner et al., 2016).

Risk factors

Pregnancy is a state of altered haemodynamics, hormonal changes and hypercoagulability and this is in itself a risk factor for initiating new heart conditions or amplifying existing conditions (Gowda et al., 2003; Smilowitz et al., 2018). All other risk factors are additive to this baseline risk. Recent research has identified a possible risk associated with hormonal therapy and assisted fertility treatments and further research in the area is warranted (Paratz et al., 2018). Lactation continuation and cessation both appear to be associated with risk for PSCAD (Saw et al., 2014; Tweet et al., 2017) and PPCM (Arany & Elkayam, 2016).

Risk factors for cardiac disease in the non-pregnant population also apply to pregnant and postpartum mothers, though the prevalence and severity of these risk factors (e.g., dyslipidaemia, hypertension, diabetes, advanced age) is often less than the non-pregnant population, even among age-matched women (Elkayam et al., 2014; Faden et al., 2016). Multiple pregnancies and multigravida increase risk and the effects of pregnancies appear additive and persisting in the majority of the literature (De Martino et al., 2019; Elkayam et al., 2014; Schlichting et al., 2019; Tweet et al., 2017; van Hagen et al., 2017).

Some cardiac diseases have specific risk factors. Aortic dissection is syndromic or non-syndromic, with the most common syndromic cause in pregnancy being Marfan syndrome (Nasiell et al., 2009; Silvestri et al., 2019; Wanga et al., 2016). Fibromuscular dysplasia (FMD) is a known risk factor for PSCAD (Chen et al., 2019; Saw et al., 2014). Geographical variances affect the risk of communicable diseases such as rheumatic fever, healthcare availability, socio-economic profile, and ethnicity differences (Dennis, 2016; Diao et al., 2011; van Hagen et al., 2018).

Timing of presentation and deaths

Timing of presentation or exacerbation varies across conditions and influences likely aetiology as well as maternal and infant outcomes (Elkayam et al., 2014). PAMI, PSCAD and aortic dissections are most common in the third trimester to early postpartum (Balgobin et al., 2020; Beyer et al., 2020; Gibson et al., 2017; Havakuk et al., 2017; Regitz-Zagrosek et al., 2018; Silvestri et al., 2019). The highest incidence of HF is late in the second trimester (34%) or peripartum (31%) (Ruys et al., 2014). Late PPCM (diagnosed six to twelve month post-delivery) is associated with 2- to 3-fold event rates in cardiac death, all-cause mortality, and MACE compared with early PPCM (diagnosed in first eight months of pregnancy) and ‘traditional’ PPCM (diagnosed last month of pregnancy till fifth month postpartum) (Wu et al., 2017).

Arrhythmias are most common in the third trimester (Lee et al., 2020) though for women with CHD arrhythmias may be most common in the second trimester (Salam et al., 2015).

Postpartum cardiac events are inconsistently reported in the literature and may be underestimated, particularly for PSCAD and PPCM (Kamiya et al., 2011; Masoomi et al., 2018; Vijayaraghavan et al., 2014), but also possibly for valvular disease (Sliwa et al., 2015). The challenge in accurately estimating the prevalence of postpartum conditions is that in addition to the chance of misdiagnosis, milder cases may not present to hospital and thus will not appear on discharge coding data.

Postpartum deaths accounts for more than 50% of combined CDPP deaths (Lameijer et al., 2020), yet this figure is likely higher as data is often limited to 42 days postpartum, where late postpartum deaths occur from 42 to 365 days postpartum (Sliwa & Anthony, 2016). In a mortality review from California approximately 70% of CMY deaths occurred in the early postpartum period (42 days from delivery) (Hameed et al., 2015). Late postpartum deaths occurred in only 5% of non-CMY cardiac deaths (aortic dissection, coronary artery disease, valve and rhythm disorders) compared with 40% of all CMY deaths and 55% of DCM deaths.

While overall maternal deaths have decreased, post-partum and late maternal deaths have not declined in the past decade (Sliwa & Anthony, 2016). Similar to reporting inconsistency seen in maternal morbidity (England et al., 2020), estimates of death are likely to be underestimated because late mortality has been inconsistently defined or may not have been counted. A demonstration of this is when a checkbox for pregnancy in the past year was added to death certificates in some US states it led to an increase in the number of late maternal deaths reported in those states (Hoyert, 2007).

Preventable morbidity and mortality, severe maternal morbidity and near miss events

Mortality studies and confidential inquiries that evaluate contributors to death provide a valuable insight into the clinical sequalae of different presentations as well as care provided. However, while mortality is the definitive outcome, it is essential to include short- and long-term morbidity outcomes in research and health services planning, including examining SMM and near miss events. Pregnancy outcomes occur on a continuum of the broad categories of normal/healthy pregnancy - morbidity - severe morbidity - near miss – death; however, in practice identifying a woman’s status along that continuum can be difficult which influences her undesirable progression along the continuum (Geller et al., 2004). Scoring systems and frameworks have been developed to facilitate assessment and improve outcomes, and as more data is examined and research into under-researched conditions is undertaken, these systems need to be continually updated and refined (Filippi et al., 2018; Geller et al., 2004).

Maternal morbidity is important for women’s quality of life, future fertility, longevity, as well as health care costs and informing health management. There is significant burden from maternal morbidity with about one in four women with cardiac disease during pregnancy requiring hospitalisation (Roos-Hesselink et al., 2013). As maternal mortality reduces, morbidity is increasing yet current maternal morbidity monitoring is affected by inconsistent definitions and criteria, language and monitoring practices (England et al., 2020).

Studies on severe maternal morbidity under-ascertain the disease burden as they do not include women who have no or mild symptoms, are undiagnosed or who have postpartum disease as they are out of scope and or do not present to hospitals. Huisman et al. (2013) reported that for each maternal cardiac death in the Netherlands, nearly eight women had severe morbidity from cardiac disease, but note that this was limited to six weeks postpartum. A study of the association between the number of SMM indicators (e.g., ICU admission, assisted ventilation, renal failure, shock, preeclampsia), and maternal death, found that of 181 maternal deaths, 68.0% (23) had at least one SMM indicator compared with 1.7% (33,152) of women who survived, reflecting a missed opportunity to intervene and prevent maternal deaths (Ray et al., 2018).

Avoidable maternal deaths from all causes occur globally but are highest in developing countries with 232.8/100,000 vs 12.1/100,000 birth in developed countries (Kassebaum et al., 2014). A stark report of nine maternal mortality reviews across the USA estimated 68.2% all of cardiovascular deaths in pregnancy up to one year postpartum were preventable (Building U.S. Capacity to Review and Prevent Maternal Deaths, 2018). Across all preventable maternal deaths patient and family factors were cited 38.2%, care provider 33.9% and systems of care 21.6%. Without analysing each case, it is impossible to ascertain if a patient factor such as non-attendance to follow-up or to take prescribed treatment was due to a patient’s informed choice, financial restraints, information and advice being poorly communicated or other factors.

A review of 37 maternal deaths, 33 near-miss morbidity and 101 other SMM found no significant differences in types of preventability (system, provider or patient) across the three groups. Overall, system factors (highest care processes) were cited in 33% to 47%, and patient factors were cited in 13% to 20% of the women with preventable events (Geller et al., 2004). Significantly, provider-related factors were cited for approximately 90% of the preventability in all 3 groups, in particular, incomplete or inappropriate management regardless of the point along the morbidity/mortality continuum. Analysis of maternal deaths due to vascular dissection found that substandard care was provided in 56% of cases, most frequently inadequate assessment of complaints and a delay in diagnosis (la Chapelle et al., 2012).

A review of CDPP in the Netherlands found that care factors may have contributed to 28% of deaths; 40% of these were patient-related (pregnancy against medical advice, underestimation of symptoms) and 60% were healthcare provider related (symptoms not recognised, delay in diagnosis, delay in referral) (Lameijer et al., 2020). This risk was highest for CMY where 43% of deaths were identified as potentially being avoidable if contributing care factors had been identified. Preventable adverse outcomes also affect foetal and neonatal outcomes, especially for cardiac disease in pregnancy, for example prematurity associated with PAMI is three times higher than in women without PAMI and causes are commonly iatrogenic (Burchill et al., 2015; Cauldwell et al., 2019).

Research on CDPP needs to include longitudinal studies to capture late morbidity and mortality and to understand long-term outcomes. Clinical care following CDPP, SMM and near-miss needs to be multidisciplinary, co-ordinated and extend beyond the traditional 6 weeks postpartum (Filippi et al., 2018). The literature supports the requirements for specialised resources and support for women in pregnancy (Costa et al., 2015), postpartum (Almalik, 2017), following severe maternal morbidity (Hinton et al., 2015b) and following a cardiac event and diagnosis (Ebrahimi et al., 2021). There is increasing numbers of multidisciplinary cardio-obstetrics clinics reporting improved outcomes for women with CDPP (Davis et al., 2021; Magun et al., 2020; Quiñones et al., 2021); however, availability remains far below what is required and often limited to large metropolitan areas in high income countries, and may not provide long-term follow-up (Sliwa & Anthony, 2016).

Study methods and types

There are several challenges in accurately estimating prevalence and outcomes. Newly defined conditions may not be captured in earlier research or may be ascribed to different conditions (England et al., 2020). Clarity of definition and diagnostic criteria is not universally established for all conditions, and diagnosis may require a level of imaging equipment and expertise not available at all sites (Masoomi et al., 2018; Vijayaraghavan et al., 2014).

Retrospective studies use hospital discharge coding which may be erroneous; this can be overcome with confirmation of diagnosis via file review by experts, however, this is a laborious and costly exercise (Ersbøll et al., 2017). Lack of specific codes can also affect accuracy, for example, Ersbøll et al. (2017) identified 207 records that met the inclusion of PPCM based on pregnancy and heart failure related codes, and upon file review found only 61 met the criteria for PPCM. Bush et al. (2011) noted that the data from UKOSS differed to the studies from the US and Japan and postulated that this may be due to their prospective study having a smaller cohort, stricter inclusion and diagnostic criteria, different demographic and management. The authors also noted inconsistency across the three UK databases that they were using. In the US the change from ICD-9 to ICD-10 coding resulted a statistically significant and clinically meaningful decrease in the incidence of SMM in hospital discharge data which was unlikely to accurately reflect any change in the population of women having babies (Metcalfe et al., 2021). Improving and changing codes and systems is essential however this needs to be taken into consideration when comparing studies using different codes and when estimating trends.

Regardless of mechanism, accuracy of data is compromised by limited large population studies, reliance on case series and case studies, under-recognition and under-coding, inconsistent testing for risk factors (e.g., FMD or anaemia) and inconsistent use of coronary angiography. Further, mortality data is calculated on a variety of sources including hospital databases, registries, pregnancy surveillance systems, confidential inquiries, autopsies and cohort studies, each of which may provide different levels of detail, and have strengths and weaknesses (Keepanasseril et al., 2021).

2.4.2 Part B: The lived experience of having CDPP

There is a gap in the literature relating to the experiences of women with CDPP. Few studies investigate the impact of breastfeeding on CDPP or the impact on mothers of abrupt cessation. Limited studies review the impact on activities of daily life, mental health effects, quality of life measures, relationships, loss of incomes and persistent risk.

Maternal mortality monitoring is an essential component of quality improvement in maternity care but it is also necessary to establish evidence-based information on cardiac presentations, cardiac related complications and women's experiences. In particular, there is a lack of comprehensive data on the impact a diagnosis of CDPP has on quality of life, psychosocial and emotional wellbeing and healthcare experiences of women during pregnancy and the postpartum period.

Women with CDPP are situated at the intersection of several and varied medical and psychological conditions, each potentially bringing significant morbidity. They are at risk of worsening cardiac disease, chronic illness, mental illness, trauma and death. Their pregnancy, labour, birth and postpartum recovery may be complicated. Their physical and mental health may negatively impact on their ability to mother in the manner they intended and desired and their quality of life may be compromised long-term. This compounded risk exposure may lead to significant and long-term negative outcomes. It is critical to understand women's experiences to develop and provide evidence-based guidelines that meet their needs in the acute hospital setting and after discharge to the community. Qualitative research is essential to provide the human domain to health and medical research. It aids clinicians in communicating, in understanding patient behaviour, and in determining to motivate patients for change. It helps researchers understand if their new intervention is tolerable or acceptable to patients. Qualitative data informs the development of guidelines and policies to both protect patients and to optimise their outcomes.

2.5 Chapter summary

This chapter reviewed the current literature on CDPP prevalence and outcomes (cardiac, QoL, mental health and reproductive). The volume of data above is due to the numerous difference cardiac diseases included, different timing of CDPP and various outcomes to consider; overall there is a lack of data in all these domains, especially in the qualitative domains. This chapter provided a framework for this thesis by describing the clinical significance of CDPP and describing the research conducted on women's experiences of CDPP. Chapter 3 describes the methodology and methods of this thesis.

Chapter 3: Methodology and methods

3.1 Chapter introduction

The literature review in Chapter 2 established that internationally 1-4% of pregnancies are complicated by cardiac disease and that prevalence is increasing (Regitz-Zagrosek et al., 2018). Cardiac disease in pregnancy and the first year postpartum (CDPP) is a leading cause of maternal mortality and it is associated with significant morbidity which may persist for many years. Chapter 2 also identified a paucity of research on women's experiences of CDPP, including their subsequent quality of life (QoL), mental health, experience of mothering and what their support needs are. The impact of CDPP is felt by the woman, her family and broader community as her ability to participate is compromised and her ongoing health needs require access to generalist and specialist services. This thesis is a response to the above identified gap in research on women's experiences and needs.

This chapter outlines the methodology and methods for this thesis and provides a rationale for the choice of a mixed methods design. Some of the methods described below are repeated in the seven chapters that follow as each is a stand-alone publication or chapter.

For methodological congruence in a research study, it is necessary that the aim and objectives, study design, questions and methods of research are logically and meaningfully interconnected and interrelated so that the study is a cohesive whole rather than fragmented isolated parts (Richards & Morse, 2013; Thurston et al., 2008). This requirement is replicated and perhaps increased for a thesis by compilation such as this one, and for mixed methods research, to ensure consistency, cohesion and lack of 'method slurring' (Baker et al., 1992). Therefore, I begin with the thesis aim and objectives to situate the decisions on methodology, study and thesis design and methods as follows.

3.2 Aims and objectives of the research

3.2.1 Aims

The aim of this thesis is to give voice to women who have or had CDPP, to characterise and enhance the understanding of women's experiences of healthcare services, the impact of CDPP on their quality of life, mental health and experiences of mothering, and to describe women's needs to identify opportunities to improve patient outcomes. This data will provide an evidence-base to inform future research and the development of clinical services and guidelines. This knowledge will facilitate person-centred care and increase the awareness of Australian women giving birth and living with cardiac disease.

3.2.2 Research objectives

The objectives of this thesis are to:

1. Obtain and analyse the healthcare experiences of mothers who have been diagnosed with cardiac disease during pregnancy or up to 1 year postpartum.
2. Understand the mental health burden of mothers who have been diagnosed with cardiac disease during pregnancy or up to 1 year postpartum.
3. Understand the effect of cardiac disease during pregnancy or up to 1 year postpartum on women's quality of life.
4. Understand the influence of cardiac disease during pregnancy or up to 1 year postpartum on women's experiences mothering.
5. Describe the self-identified needs of Australian women with CDPP.
6. Identify opportunities to enhance care and outcomes.

3.2.3 Research questions

In order to achieve the above aim and objectives this project will answer five (5) research questions as follows.

1. What are the healthcare experiences of women who have CDPP?

2. What is the impact of having CDPP on women's mental health?

3. What is the impact of having CDPP on women's experience of mothering?

4. What is the impact of having CDPP on women's quality of life?

5. What are the needs of women with CDPP?

3.3 Methodology and research design

3.3.1 Definitions

The definitions of methodology and mixed methods can vary among writers, so it is important to be clear about the interpretation adopted for this thesis. Methodology (sometimes called the research paradigm in qualitative research) refers to the philosophical framework and fundamental assumptions and characteristics of research, and what it means to be human which is associated with specific research methods (Van Manen, 2016). Methodology then is the theory informing research, and the study of what methods are appropriate for any given research project. Research design is the plan of action which for coherence, necessarily links your philosophical assumptions to specific methods (Creswell & Plano Clark, 2011). That is, the research design is a bridge between your philosophical framework and the tasks of research; see *Figure 3.1*. Methods are more specific, they are the individual tasks or techniques of research, such as how you collect data (Creswell & Plano Clark, 2011).

Figure 3.1*: Relationship of research components*

3.3.2 Methodology

This research explores the under-researched areas of women's experiences and needs, and contends that women's experiences and interpretations of those experiences are formed through apparently oppositional forces. That is, constructivism in which meaning and knowledge is formed through the cognitive process of the individual and social constructivism in which there is a multiplicity of realities which are constructed through our interactions with others, and situated within social structures that determine power and oppression (Andrews, 2012; Charmaz, 2006; Gergen, 2015). Whilst constructivism and social constructionism appear antithetical, both have at their core, an understanding that experiences are central to generating knowledge and understanding (Guba & Lincoln, 1994; Scotland, 2012). I believe, especially with study and self-reflexivity, a functional tension between the two may yield the fullest understanding, and that 'both and' is more plausible than an 'either or' position. That said, overall, a more social construction analysis is undertaken in this thesis, for example, considering issues of power and gender in Chapter 5, while a constructivist approach is incorporated in some discussion, such as seen in discussions on self-identity on Chapter 6. See *Table 3.1* for further detail. A mixed methods research design is used and this facilitates the inclusion of a breadth of related philosophical approaches in addition to pure social constructionism, in particular, at times analysing and interpreting the data through the lenses of critical theory, feminism and participatory advocacy.

3.3.3 Mixed methods research

Defining mixed methods research is both simple and complex. A clear and concise definition is that mixed methods research collects and analyses both quantitative and qualitative data, integrating (combining) them in order to provide a more inclusive and complete understanding of a research problem (Creswell & Plano Clark, 2011). However, Johnson et al. (2007) asked leading researchers for their definition of mixed methods research and reported nineteen overlapping but different answers, reflecting that the articulation of the defining characteristics of mixed methods research is still in evolution. Johnson et al. (2007) offer the following definition based on the analysis of answers received above.

> *Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration.* (Johnson et al., 2007 p123)

In mixed methods research the quantitative and qualitative data may be integrated within one single study or across several different studies such as in a thesis (Bazeley, 2018). Researchers using a mixed methods approach aim to overcome the limitations (cancel out respective weaknesses of one or the other) of using only quantitative or qualitative research to deepen, broaden, or corroborate the understanding of a phenomena (Bazeley, 2018; Johnson et al., 2007; Tashakkori & Teddlie, 2016).

It is noted that some writers consider mixed methods as a methodology, and others describe it as a method (Creswell & Plano Clark, 2011). I have adopted the approach of Creswell and Plano Clark (2011) and consider mixed methods to be a research design informed by philosophical assumptions, using both qualitative and quantitative methods of inquiry. That is, the methods of data collection and analysis are informed by the philosophical assumptions of the research.

Mixed methods research often adopts a pragmatism paradigm (Johnson & Onwuegbuzie, 2004). Pragmatism's ontological perspective is also interpretive, where reality is constantly renegotiated, however reality is viewed in terms of its usefulness in new circumstances (Allemang et al., 2022). Pragmatism's epistemology is focused more on best method being one that solves a problem; finding out is the means and change is the underlying aim. The theoretical perspective is often based on Dewey's work and the notion of research through design; and concepts only being relevant if they support action (Allemang et al., 2022). Thus, mixed methods supported the aims and objectives of this research, but pragmatism did not.

I align with the approach of "methodological eclecticism" described by Teddlie and Tashakkori (2012) in which researchers combine methods to choose what they believe are the best tools to thoroughly investigate a phenomenon of interest. Further, Teddlie and Tashakkori (2012) explain that contemporary mixed methods research is characterised by "paradigm pluralism", or the view that a variety of paradigms may provide the philosophical framework, including but not limited to pragmatism (e.g., critical theory, social constructionism, the dialectic stance, critical realism, feminism). A paradigm pluralism is adopted in this thesis, for whilst it is founded in social constructionism, the interweave of feminism and participatory advocacy is illustrative of pluralism and of the characteristic of contemporary mixed methods research of "*an emphasis on continua rather than a set of dichotomies*" (Teddlie & Tashakkori, 2012 p776).

Qualitative research is a form of social inquiry that focuses on the way people make sense of, and the meanings they ascribe to their experiences and the world in which they live, making it appropriate to explore the experiences of the participants (Denzin & Lincoln, 2011). A phenomenological qualitative *approach* (but not method) is employed as it fits inquiry into a topic where there is little or no existing body of knowledge. This approach privileges the voices of participants as they describe their lived experiences, and it seeks to find commonality across the subjective, lived experiences of a phenomenon within a particular group (Creswell & Poth, 2018).

A quantitative study design is appropriate to estimate the impact of CDPP on women's quality of life, mental health and experiences mothering. Quantitative research is measurable, has rigour, is replicable and can be analysed in relation to other studies using the same tools.

3.3.4 Rationale

There is a dearth of qualitative and quantitative data on CDPP in Australia and limited international data; employing a mixed methods approach enables a comprehensive, richly descriptive investigation of CDPP, which would not be possible employing only one method (qualitative or quantitative) (Creswell & Poth, 2018; Tashakkori & Teddlie, 2016). This research design provides insight from multiple perspectives, increasing its relevance and usefulness in considering clinical, research and education responses to addressing complex and diverse needs of this population.

CDPP includes a variety of acquired, congenital and genetic conditions of varying severity and complexity. Treatments vary over time and between the different conditions. Women may be diagnosed anywhere from when they were born through to twelve months after they themselves give birth, meaning they may have had their cardiac condition their whole lives or it may be new in adulthood. CDPP is within the domain of multiple specialty areas (maternal health, cardiac, anaesthetics, rehabilitation, emergency, general practice and community health) and multiple disciplines (including medical, nursing, midwifery, rehabilitation, allied health and mental health). Other variables include the number of children a woman has, and her environmental and social determinants of health. This multi-level complexity of CDPP is characteristic of 'wicked problems', a term coined by Rittel and Webber and adopted by Mertens in the context of mixed methods research (Mertens, 2015).

> *Wicked problems as those that involve multiple interacting systems, are replete with social and institutional uncertainties, and for which only imperfect knowledge about their nature and solutions exist.* (Mertens, 2015 p3)

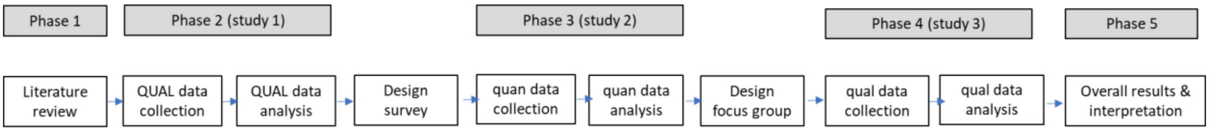
Further, the incompleteness of understanding the complex issue defies a singular, definitive solution. Or in this case, a singular research approach producing a singular finding is insufficient in addressing the wicked problem of CDPP (Mertens, 2015).

3.3.5 Research design

This thesis uses a multiphase exploratory sequential mixed methods research design in which both qualitative and quantitative studies are used (Schoonenboom & Johnson, 2017); see *Figures 3.2 and 3.3*.

In Study 1 the qualitative interviews were "exploratory" and served to provide a basis of understanding of women's experiences. The qualitative interview data analysis informed the choice and modifications of quantitative instruments used in Study 2 (Creswell & Plano Clark, 2011). Study 2 expanded upon the exploratory nature of Study 1 and added breadth and quantitative data. Study 3, the focus groups, were "explanatory" and provided additional qualitative detail and interpretation to the quantitative needs assessment that was part of Study 2 (Creswell & Plano Clark, 2011; Ivankova et al., 2006).

Figure 3.2: *Research design*

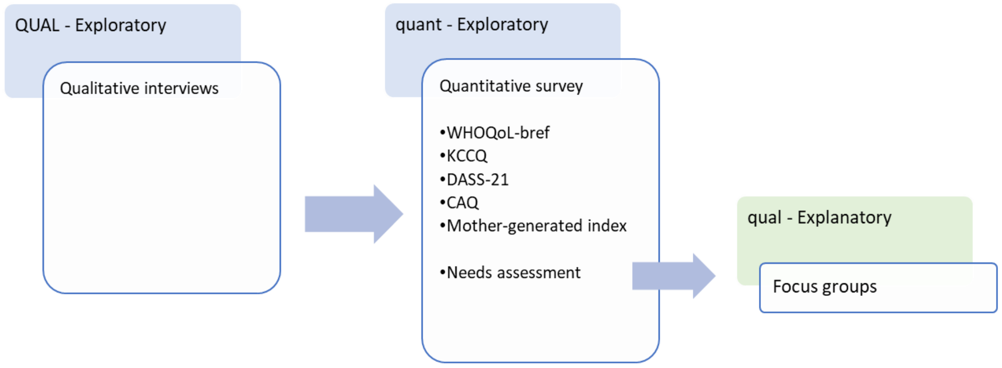


Weighting of the studies

The mixed methods research design has a weighting towards qualitative research which is augmented by the quantitative study. The logic of my inquiry and approach to data is inductive.

QUAL > quant > qual

Figure 3.3: *Sequential mixed methods design weighting and components*



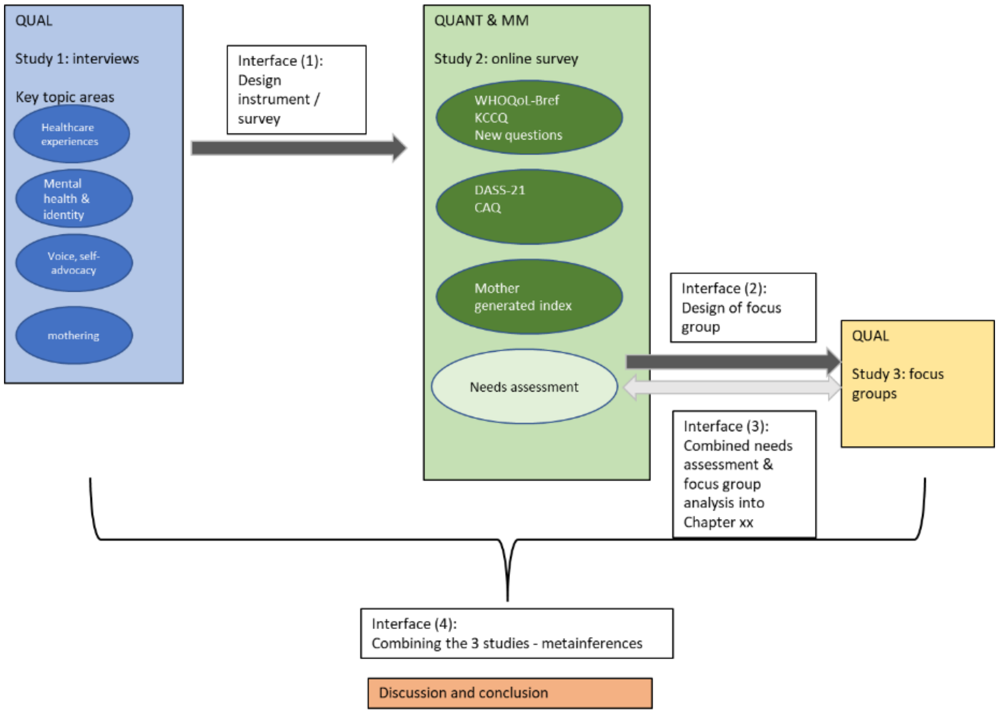
Timing

The design of this thesis was emergent and this is reflected in the timing of the studies. Timing of studies relates to the order or sequencing of individual components or studies, and the relationships between studies. Simultaneity describes whether the data is collected concurrently or sequentially. Dependence indicates whether the implementation of one study or component was dependent on the data analysis of a preceding study or component (Schoonenboom & Johnson, 2017). In this thesis, the three studies were sequential and dependent. Analysis of Study 1 determined the design of Study 2, and Study 2 results determined the design of study 3.

Interface and integration

Integration is *"the creation of purposeful interdependence between methods and/or their associated analyses"* (Bazeley, 2018 p19). Points of integration (or interface) between the qualitative and quantitative studies are defining of mixed methods research, and this 'mixing' or integration can occur at different stages and in different ways (Creswell & Plano Clark, 2011). Teddlie and Tashakkori (2009) nominate four possible points of integration: study conceptualisation, data collection, data analysis, and the inferential stage. Guest (2013) proposes a more nuanced approach that better describes this thesis. Moving from integration as being mixing of whole studies, he proposes an approach of 'points of interface' between two data sets. The point of interface refers to any point in a study where two or more data sets are mixed or connected in some way. Schoonenboom and Johnson (2017) expanded on Guest's approach to define the point of interface/integrations as any point in a study where two or more research components are mixed or connected in some way. Thus, the points of interface in this thesis are as follows, as per *Figure 3.4*.

Figure 3.4: *Points of interface*



- Point of interface 1: Using the results from Study 1 to determine what instruments were used in study 2.
- Point of interface 2: Using the results from the Needs Assessment within Study 2 to design the Focus groups (Study 3).

- Point of Interface 3: Combining the results of the needs assessment and the Focus Group in the needs assessment report (Chapter 10).
- Point of interface 4: Combining the analysis of all studies in the thesis discussion and developing meta-inferences.

Table 3.1*: Thesis coherence; methodology, research design and method*

Philosophical perspective	*Constructivism - my view informing this thesis*	*How I apply it*	*Research design*	*Methods*
Ontology (What is the nature of reality?)	There is no single truth, rather truth is socially constructed	→	Mixed methods research design. This thesis sought to understand women's experiences through multiple data collection approaches, using in-depth interviews and subjective quantitative instruments. The focus groups and needs assessment facilitated a component of participatory advocacy. Privileging the voices of the women who participated in this research reflects the value attributed to their experiences. Qualitative analysis used reflexive thematic analysis which values the role of the subjective researcher as integral to the interpretation of the data.	Includes multiple voices and perspectives, liberal use of participant quotes. Qualitative and quantitative methods increased the scope for capturing and representing multiple realities. Multiple quantitative instruments enhanced data diversity.
Epistemology (How can I know reality? What is the nature of knowledge and its generation? What is the relationship between the researcher and research subject?)	Reality and knowledge need to be interpreted by analysing past events and experiences of the participant, acknowledging the interpretive influence of the researcher.	→		A social constructivist lens is used in data analysis, as well as considering critical theory and feminism because power and relationships are key to understanding patient experiences of and within the healthcare system, and their broader lives.
Axiology (What is the role of values?)	Research is biased and value-bound. The researcher is intrinsic to the research, not simply an observer.	→		I use reflexive thematic analysis which positions the researchers' subjectivity as a resource, and allows for thick description, interpretative story-telling and nuanced theme development. Selection of qualitative instruments reflects my research priorities and interests. Analysis is descriptive.

3.4 The research studies and data collection methods

3.4.1 Setting and sample

Setting

Women who had cardiac disease in pregnancy or the first year postpartum while living in Australia. Participants may have accessed private or public healthcare. Interviews were conducted via phone and the focus groups were online, with participants primarily at home, or in some cases, at their workplace. The online survey was completed wherever was convenient to the participants.

Sample

The inclusion and exclusion criteria were the same for Studies 1 and 2; participants for Study 3 were drawn from Study 2.

Inclusion criteria

Mothers who have been diagnosed with cardiac disease prior to, during pregnancy or up to 1 year postpartum, living in Australia and who give birth to one or multiple babies beyond 20 weeks, gestation or 400gm or greater birthweight. The women could have a range of different conditions, including: valvular heart disease, aortopathies, cardiomyopathies, rhythm disorders, congenital heart disease, ischaemic heart disease, and recipients of heart transplants. Women required adequate English fluency to participate in the interview.

Exclusion criteria

Mothers who have been diagnosed with cardiac disease outside the timeframe or were living outside of Australia at the time of the pregnancy or postpartum year. Cardiovascular diseases excluded are hypertension, pre/eclampsia and thromboembolic disease.

3.4.2 Study 1: qualitative interviews

Study design

A qualitative study was designed to examine women's experiences of CDPP and privilege women's voices to increase knowledge and ultimately improve clinical care and quality of life. Qualitative research focuses on the way people make sense of, and the meanings they ascribe to, their experiences and the world in which they live (Denzin & Lincoln, 2011). A phenomenological perspective is adopted as it is fitting for areas with little existing knowledge, and focuses on the commonality of subjective, lived experiences of a phenomenon within a particular group (Creswell & Poth, 2018). The concept of the study was discussed with clinical and community groups from the NSW Heart Foundation.

Recruitment and sample size

Criterion-based purposive sampling was used to engage women who had a diagnosis of CDPP and were willing to participate in an in-depth interview (Palys, 2008). Participation was voluntary and did not attract any financial benefit.

The population we sought to interview was both ill-defined and hard-to-reach due to a lack of prevalence data, the inclusion of rare and uncommon conditions, limited registries and disease-based support groups and to our knowledge no support groups specifically for CDPP (Wozney et al., 2019). Online recruitment has been shown to be effective for recruitment for hard-to-reach groups (Whitaker et al., 2017), therefore I contacted representatives from the following registries, and research and support organisations who shared study recruitment material in emails and newsletters, and posted on the Facebook pages: Adult Congenital Heart Disease Australia, Australian Genetic Heart Disease Registry, Australian SCAD Support, Cardiomyopathy Australia, Heart Kids, Heart Support Australia, Hearts 4 Hearts, Her Heart, SCAD Research Inc, and The Heart Foundation. Thirty-three women responded of which 25 women met the inclusion criteria and agreed to proceed with an interview. Recruitment was from December 2018 to April 2020, and continued until we had adequate depth and breadth of data to sufficiently describe and analyse the participants' experiences and answer our research questions (Braun & Clarke, 2021a, 2021b). Participant characteristics are provided in Appendix 1.

Data Collection

Semi-structured interviews were used because they are an established qualitative approach when exploring topics about which little is known, focus on the issues that are meaningful for the participant, and allow for diverse perceptions to be expressed (Cridland et al., 2015).

An interview guide was developed with the lead question *"Can you tell me about your experience [of having cardiac disease during pregnancy or after the birth of your baby]?"* (Appendix 2) Additional open-ended questions were formulated during the interviews in response to the participant's story and where appropriate, prompts were used to clarify and expand on the account provided. This approach facilitated an open discussion and encouraged the participants to direct the narrative of their story, and include feelings, attitudes and reflections in their own words.

Data were collected via individual interviews conducted by phone. Interviews began with confirmation of informed consent and the collection of basic demographic data. With the women's permission interviews were audio-recorded or hand-transcribed verbatim, including notable non-verbal responses such as crying or laughing. Participants were asked to choose a pseudonym to protect their identity and personal details including names and addresses were not recorded with the study data. Information was re-identifiable only to the interviewer. Interview audio was transcribed verbatim by a confidential transcription service.

Reflexive accounts of the interviews were journaled at the completion of each interview. These notes included reflections on tone, engagement and any aspect of the interview not captured in the transcription. In addition, several participants added comments after the recording stopped or email additional information they recalled, and these were added to the transcription notes.

3.4.3 Study 2: quantitative survey

Study design

A quantitative exploratory descriptive study developed in response to the findings of Study 1, qualitative interviews. In particular, this study sought to explore and expand upon findings of ongoing reduced quality of life and mental health challenges and impacts on women's experiences mothering. In addition, a needs assessment and expression of interest to participate in a focus group was included.

Recruitment and sample size

The recruitment for this study employed the same strategies as for Study 1, plus participants in Study who had provided consent to be contacted for future research were emailed study information, and a study Facebook page was established.

For 95% confidence level (Z Score 1.96), and accounting for 5% margin of error, the sample size was calculated using the Qualtrics online sample size calculator which indicated the ideal sample size of 369 participants based on an average of 300,000 births a year in Australia and a 3% incidence rate of cardiac disease during pregnancy -based on international estimates of 1-4% (Regitz-Zagrosek et al., 2018).

Recruitment ran from August to November 2021. Most participants responded within 24 hours of a social media post or email, and responses rapidly reduced over time. I did not reach the desired number of participants and note that recruitment was occurring in the third wave of Covid-19, with community fatigue and disengagement, and a saturation with online interaction which may have been a factor. In addition, with no prevalence data for CDPP in Australia, it is difficult to estimate what percentage were actually recruited. It was decided to conclude recruitment and proceed to perform exploratory descriptive analysis of the data available. Participant characteristics are provided in Appendix 3.

Data collection

Data were collected from an anonymous online survey using the Qualtrics Software (Nov 2021). A combination of survey instruments was employed to capture a breadth of data on this under-researched population. Further, CDPP includes variety of timing of diagnosis and of diseases, thus no existing cardiac or maternity patient-reported outcome measure (PROM) was applicable for all participants. Both QoL and mental health were assessed using generic tools to allow comparison across populations and medical conditions as well as disease-specific tools which were more sensitive. An instrument specifically exploring mothering experiences was included as well as a needs assessment. Survey instruments are outlined in *Table 3.2* and copies of the instruments are provided in Appendix 4.

Table 3.2*: Survey instruments*

Domain	**Generic**	**Specific**
Quality of life	WHOQoL-Bref	Modified Kansas City Cardiomyopathy questionnaire
Additional		Newly formulated questions
Mental health	DASS-21	Cardiac anxiety questionnaire
Mothering		Modified Mother-Generated Index
Needs assessment		Needs assessment

Instruments

WHOQoL-Bref

The WHOQoL-Bref was chosen as the generic QoL instrument because its theoretical construct is based on a broad concept of QoL and health that is not limited to biomedical aspects. The WHOQoL-Bref is a well-established validated tool, used in studies on a variety of physical conditions such as CHD (Areias et al., 2013), postpartum (Webster et al., 2010), rheumatoid arthritis (Taylor et al., 2004), depression (Amir & Ramati, 2002), posttraumatic stress disorder (Johansen et al., 2007) and anxiety and stress (Rusli et al., 2008).

The Australian WHOQoL-Bref questionnaire is an abridged version of the WHOQoL-100 (Murphy et al., 2000). It contains 2 global questions (overall QoL and health satisfaction) and 24 questions divided into four domains of; physical health (7 items), psychological health (6 items), social relationships (3 items) and environment (8 items). For this study we excluded Q26 *"How often do you have negative feelings such as blue mood, despair, anxiety, depression?"* due to repetition with other instruments in the study, leaving 5 items in Domain 2. Each item is rated on a 5-point Likert scale. The raw domain scores are scaled in a positive direction and transformed to a 0-100 scale for comparison with WHOQoL-100. The two global questions are scaled in a positive direction with a score range of 1-5. Higher scores for both the domains and the global questions indicate higher QoL. Domain scores were calculated according to the Guide and transformed to be out of 100 (Bulk et al., 2019).

Modified Kansas City Cardiac Questionnaire (KCCQ)

The KCCQ is a health related QoL (HRQoL) instrument for individuals with heart failure that quantifies the domains of physical limitations, symptoms, self-efficacy and knowledge, social interference, and QoL (Green et al., 2000; Spertus & Jones, 2015). The KCCQ focus is on the presence, severity, and impact of heart failure symptoms on functionality. Item responses are coded sequentially (e.g., *"not at all satisfied"* to *"completely satisfied"*) from worst to best status. We have incorporated adaptations to the KCCQ by Koutrolou-Sotiropoulou et al. (2016) relating to work status, counselling and future pregnancies. These items were coded on a scale, and some also included free text sections.

The cardiac HRQoL was augmented by including modified questions relevant to mothers and younger patients such as concerns regarding longevity, their children, finances, sex and access to care from a recent study on women with peripartum cardiomyopathy (PPCM) (Rosman et al., 2019). This study included women with a diversity of cardiac diagnoses so the above cardiac HRQoL tools were modified to be applicable for all participants. Novel questions were developed to distinguish between information and counselling provided at time of diagnosis, rate the quality of information and communication, determine if counselling was provided in response to advice to avoid having further children and what impact that advice had on participants, and frequency of missing medical appointments due to cost. These new questions were developed after the qualitative study which found a lack of recognition of the mental health impact of CDPP in both the short and long term, and subsequent lack of mental health support provided or referred to. Affirmative responses to scaled questions were consolidated to a single positive response (e.g., a little, moderate, very) for the purpose of analysis.

Both the WHOQoL-Bref and the KCCQ include measures more accurately described as measures of disability, or limitation, such as ability to walk around the block, and these are possibly more applicable to an older population (Carr et al., 2001; Higginson & Carr, 2001). Most of these types of questions were retained to facilitate comparison of results. Other items measured clinical outcomes rather PROs, such as ejection fraction and blood pressure and these were removed as they were not patient centred.

Depression, Anxiety, and Stress Scales-21 (DASS-21)

The DASS is a validated self-report scale with three subscales of depression, anxiety, and stress (P. F. Lovibond & S. H. Lovibond, 1995; S. Lovibond & P. Lovibond, 1995). The DASS was chosen as the general mental health instrument as it differentiates between depression, anxiety and stress, is short and simple to complete, and is a key tool used in research, general practice and mental health services in Australia (Crawford et al., 2011). The DASS has been validated in a variety of settings and with diverse age groups; the shortened version, DASS-21, has also been found to be valid and reliable (Akin & Çetin, 2007; Henry & Crawford, 2005; Osman et al., 2012) and was used in this research as it was more manageable for participants when it was embedded in the larger survey.

The depression subscale items focus on low mood, hopelessness, low self-esteem, ability to feel pleasure and inertia. The anxiety subscale items focus on physiological arousal, situational anxiety, and feelings of panic and fear. The stress subscale items focus on difficulty in relaxing, impatience, irritability, and chronic non-specific arousal. Each subscale has 7 items, all answered on a Likert scale from 0 (*"Did not apply to me at all"*) to 3 (*"Applied to me very much, or most of the time"*) (S. Lovibond & P. Lovibond, 1995; Shea et al., 2009). The scores for the total DASS-21 and for each subscale are summed, with low scores reflecting better mental health.

Cardiac Anxiety Questionnaire (CAQ)

The CAQ was used as a specific assessment of cardiac anxiety, which is apprehension and fear related to cardiac-related stimuli and sensations (Eifert et al., 2000). The CAQ has 18 items with 3 subscales of fear (8 items), avoidance (5 items), and heart-focused attention (5 items). Each item is rated on a 5-point rating scale from 0 ("never") to 4 ("always"). The total score is calculated as the mean of all items. Subscale scores are calculated as the mean of the relative frequency ratings for each of the items in each subscale. There are no validated clinical cut-off scores however according to the grading of the items, a higher total and subscale scores indicate greater cardiac-related anxiety (Eifert et al., 2000; Hoyer et al., 2008).

Modified Mother-Generated Index (MGI)

The MGI is a quantitative QoL instrument that also allows qualitative analysis; it was used in this thesis as primarily quantitative (Symon et al., 2015; Symon, McGreavey, et al., 2003). The MGI is adapted from the Patient-Generated Index individualised QoL measure to be applicable for mothers and is used in pregnancy and the postpartum (Symon et al., 2015; Symon, MacKay, et al., 2003) and has been validated including in other languages and transcultural applications. (Grylka-Baeschlin et al., 2015; Hendrych Lorenzová et al., 2019; Symon, McGreavey, et al., 2003). The MGI is a subjective tool in which the mother determines the content, reflecting what is most important to her, rather than responding to preformulated questions. There are scant data on what is important to, or the experiences of women with CDPP, hence I chose the MGI as it gave an opportunity to the participants to have a voice, and for researchers to begin to explore the topic from the woman's perspective.

Consisting of a three-step questionnaire the MGI can be conducted as an interview or independently completed by participant; we administered the MGI as part of the online survey. I modified the MGI to be more specific for women with CDPP, changing the instructions in step 1 from asking the participants to "*think of the most important areas of your life that have been affected by having a baby*" to "*think about the most important areas of your life that have been affected by having a baby as a woman with a cardiac condition*".

Needs Assessment

A brief needs assessment was constructed, informed by the results of Study 1, interviews.

Participants were asked to rate nine possible resource and support options (from "not useful at all" to "extremely useful") and had the opportunity to add suggestions not listed. The question was: *Thinking back to when you were pregnant or in the first year postpartum with cardiac disease, how helpful do you think the following would have been?*

3.4.4 Study 3: qualitative focus group

Study design

Online focus groups were used to answer the research question: "*What are the key features of peer support, cardiac link nurses and counselling (the highest rated resource and support options in the previous survey results) that participants need and value the most?*"

Recruitment plan and sample size

An expression of interest to be involved in this focus group was included at the end of the online survey (Study 2). Women were provided with the proposed dates and times of the focus group, consent and participant information sheet, information of counselling referrals and support options (as part of the risk assessment and distress protocol) and a brief overview of the key findings of the online survey and interviews, focusing on the results of the needs assessment question. Participants then provided consent and were sent a Zoom link and guidelines for participation in the focus group. Eighteen women submitted an expression of interest. Ten agreed to participate, two of whom were too unwell to participate on the day, leaving two focus groups of four women. Participant characteristics are provided in Appendix 5.

Data collection

The focus groups were conducted online in a secure Zoom meeting. The sessions were facilitated by myself with one or two co-facilitators/observers (Dr Jane Frawley and Professor Elizabeth Sullivan). The focus groups took between 65 and 75 minutes, and were recorded with the participants permission. The questions were semi-structured to allow flexibility and responsiveness. Participants were provided with preparatory notes one week before the focus group. A draft report of findings of the focus group was provided to the participants for their review, with three participants providing feedback. (See Appendix 6 Focus group guide.)

3.5 Data analysis

Data were analysed sequentially and combined as follows.

3.5.1 Qualitative analysis: study 1 interviews,

For the qualitative interviews (Phase/study 1) interpretive inductive data analysis was performed using the reflexive thematic analysis (RTA) approach by Braun and Clarke (Braun & Clarke, 2006, 2021a, 2022).

Inductive RTA was used as it is theoretically flexible and accessible, and responsive when unexplored phenomena are described; allowed for nuanced theme development; facilitated the coding and organisation of a large and complex data set; and it is able to highlight similarities and differences across the data set (Braun & Clarke, 2021a; Byrne, 2022). Further, RTA was used as is positions the researchers' subjectivity as a resource and it highlights the researcher's active role in knowledge production (Braun & Clarke, 2019; Byrne, 2022). Critical to the values and aims of this thesis, RTA allows for thick description and interpretative story-telling (Braun & Clarke, 2006, 2019, 2022; Gillberg & Jones, 2019).

Informed by the six stages of analysis outlined by Braun and Clarke (Braun & Clarke, 2006, 2021a) (familiarisation, code generation, theme development, reviewing and refining themes, defining themes and report writing) data coding and preliminary theme generation occurred concurrently with the interview fieldwork and was iterative and responsive to new data and developing patterns.

All study team members listened to the interviews and read the transcripts. I led the analysis by immersing myself in the data and developing and refining codes and themes and selecting illustrative quotations. Codes are understood to represent the researcher's interpretations of patterns of meaning across the dataset, and thus are generated by the researcher, and not passively received as a gift of the data (as 'themes emerged') (Braun & Clarke, 2019, 2022).

The approach to analysis evolved and differed with the various foci of chapters. For Chapter 4 the approach to analysis was essentialist/realist (reporting on the experience, meanings and reality of participants) with semantic themes (reflecting the explicit content of the data) (Braun & Clarke, 2022). For Chapters 5, 6 and 7, the approach to analysis was more interpretive as I sought to explore and understand the patterns and meanings within the data. This approach of generating latent themes is deeper and richer than coding for semantic themes as it identifies, reveals, and advances arguments for the underlying assumptions, meanings, ideologies and significance that are expressed in the stories and semantic themes (Braun & Clarke, 2022).

3.5.2 Quantitative analysis: study 2 survey

Quality of life and mental health measures

Data were summarised using descriptive statistics and included frequencies and percentages for categorical data, with ranges, means, and standard deviations for continuous data. Validated instruments were scored according to the requirements of each instrument. Time since diagnosis or pregnancy, timing of diagnosis, and category of disease were used as independent variables. Time since diagnosis was categorised as < 18 months or ≥ 18 months. Timing of diagnosis was before pregnancy, during pregnancy, or postpartum. Categories of disease were acquired, congenital and genetic heart disease. The initial plan of statistical analysis was not able to be realised due to insufficient participant numbers.

Mother-generated index

The Mother-generated index was scored according to the instructions for this validated instrument, and in addition the areas of women's lives that they reported as having been affected since having a baby as a woman with cardiac disease were coded into subdomains and domains.

3.5.3 Qualitative analysis: Study 3 focus groups

The overarching goal of this study was to develop recommendations for government and non-government organisations and health professionals on strategies to improve support and resources for women who have CDPP. The objective was to expand upon the results of the needs assessment contained within the online survey, to understand the perspectives of participants and to undertake a preliminary exploration of options for future resource development and support. Therefore, a summary-based approach to data analysis was adopted and a report of findings was produced, as opposed to a thematic analysis.

3.5.4 Mixed methods data analysis integration

Data was integrated at a chapter level and the thesis level, as outlined above in 3.3.5 Research design. Data merging or integration in mixed methods research distinguishes it from multiple methods research projects where data from the various methods is not integrated (Creswell & Plano Clark, 2011; Onwuegbuzie & Johnson, 2006).

The thesis used a multiphase exploratory sequential mixed methods study design. That is, it followed the typical exploratory sequential design of a qualitative study followed by a quantitative, with the addition of another phase with Study 3, the focus groups, in which qualitative data builds on and explains the value of the resource options in the needs assessment. The timing and manner of integration needs to reflect the purpose of conducting a mixed methods study. The following classification of purposes of mixed methods research by Greene et al. (1989) remains a common guide.

- *Triangulation*: seeks convergence, corroboration, correspondence of results from the different methods.
- *Complementarity*: seeks elaboration, enhancement, illustration, clarification of the results from one method with the results from the other method.
- *Development*: seeks to use the results from one method to help develop or inform the other method, where development is broadly construed to include sampling and implementation, as well as measurement decisions.
- *Initiation*: seeks the discovery of paradox and contradiction, new perspectives of frameworks, the recasting of questions or results from one method with questions or results from the other method.
- *Expansion:* seeks to extend the breadth and range of inquiry by using different methods for different inquiry components.

Mixed methods data analysis for this thesis included complementarity, development and expansion. Complementarity and expansion are common in complex, multiphase research design (Greene 2007; Onwuegbuzie & Collins 2007). The sequential studies sought to complement and build on the previous studies, elaborating on results, and using multiple studies and instruments expanded the scope and breadth of understanding possible. Development is reflected in the use of data from Study 1 informed the development of study 2, which in turn informed the development of Study 3.

At the completion of the three studies, further analysis was performed by integrating the quantitative and qualitative data to provide a more comprehensive understanding of the topic (Bazeley, 2018; Cameron, 2009). The final integration of data is presented in the discussion chapter where the analysis and conclusions (‘inferences’) of the individual studies are integrated and interpreted to form “meta-inferences” (Teddlie & Tashakkori, 2009).

3.6 Data Management and Storage

All data including audio recordings, signed consent forms, transcripts and survey data were stored in a secured password protected directory on the password protected computer of the researcher for the time of data collection and analysis. According to requirements by the *Australian Code for the Responsible Conduct of Research*, for data storage and backup safety, confidentiality and for ethics approval, a research data management plan used Stash for the ongoing management and storage of data. Data will be stored for the period of five years from the date of any associated publication. After this time all data will securely be destroyed using the required process for destruction of confidential information.

3.7 Ethical considerations

3.7.1 Ethics approval

Each study included in this thesis was approved by the Human Research Ethics Committee of the University of Technology Sydney as follows; copies are provided in Appendix 7.

Study 1

- ETH18-2970 Health care experiences of first-time mothers with pre-existing or newly diagnosed cardiac disease

- ETH19-3372 Health care experiences of mothers with pre-existing or newly diagnosed cardiac disease (Modification of ETH18-2970).

Study 2

- ETH21-5695 Quality of life following cardiac disease in pregnancy and the first 12 months postpartum

Study 3

- ETH21-6641 Needs assessment: cardiac disease in pregnancy and the 12 months postpartum

3.7.2 Potential risks

Assessment for risk of harm and distress protocols were developed for each study and ethics application. The primary risk for participants was emotional distress. Embarking on a first pregnancy with a known cardiac condition, or receiving a diagnosis of a cardiac condition during the first pregnancy can be distressing, and therefore, it is possible that talking about their experience or completing a survey could prompt an emotional response. It is also possible that a participant may have suffered a pregnancy loss, or that the baby was stillborn or died shortly after birth. Within the focus group there was a risk of participants feeling self-conscious contributing in a group setting. Additionally, there is the inconvenience for women of giving up their time.

3.7.3 Risk mitigation strategies

The researcher and supervisors are experienced researchers and clinicians and their accumulated experience ensured that each study was undertaken in an appropriate manner at all times. I conducted the interviews in a sensitive and supportive manner to minimise any potential for distress. I have conducted group work and interviews on a range of sensitive topics such as sexual and reproductive health, cancer survivorship, burn-out and resilience, conflict, boundaries, workplace bullying and harassment, and workplace re-structures and this experience enabled me to perform data collection competently and safely.

Distress protocols were established for each study and participants were provided with support details on numerous occasions (e.g., in the Participant Information Sheet, Consent Form, beginning of each data collection, within the survey, and at completion of each data collection).

3.7.4 Pre-existing relationships

Participants of Study I were invited to participate in Study 2, and an unknown number did (Study 2 was an anonymous online survey). All participants of Study 2 were invited to submit an expression of interest to contribute to the Focus Groups, of the nine women who participated in the focus group, five had also been participants of Studies 1 and 2. No participant was directly approached to participate in the focus group. No relationships existed outside of the conduct of the research and there was no conflict of interest.

3.8 Chapter summary

This chapter has outlined the theoretical underpinnings and research design for this thesis. The multiphase exploratory mixed methods research was conducted in two phases using multiple study designs and instruments in order to meet the aims and objectives of the research, that is, to characterise and enhance the understanding of women's experiences of healthcare services, the impact of CDPP on their quality of life, mental health and experiences mothering, and to describe their needs in order to identify opportunities to improve patient outcomes.

The following chapters describe the studies in more detail, with the next chapter presenting the analysis of women's healthcare experiences derived from Study 1.

Chapter 4: The healthcare experiences of women with cardiac disease in pregnancy and postpartum: a qualitative study.

4.1 Publication

The results of this section have been published as follows:

Hutchens, J., Frawley, J., & Sullivan, E. A. (2022). The healthcare experiences of women with cardiac disease in pregnancy and postpartum: A qualitative study. *Health Expectations, 25:* 1872- 1881.

4.2 Chapter introduction

Chapter 1 outlined the healthcare context for women with cardiac disease in pregnancy and the first twelve months postpartum (CDPP), describing both cardiac and obstetric services. In addition, Chapter 1 established the significance of this research project and documented the research questions, including Question 1 which is the focus of this chapter, *"What are the healthcare experiences of women who have CDPP?"* Chapter 2 reviews the current international literature relating to CDPP, both epidemiological data on CDPP and women's experiences of CDPP, noting that there is a lack of comprehensive data on women's experiences. Currently, all of the limited research on women's experiences of being diagnosed with CDPP is international, and a notable theme is of women losing trust in the health system after having their symptoms dismissed by health care providers and of incorrect initial diagnoses (de Wolff et al., 2018; Dekker et al., 2016; Patel et al., 2016). This chapter focuses the healthcare experiences of women diagnosed with CDPP in Australia.

4.3 Background

Cardiac disease in pregnancy and postpartum (CDPP), pre-existing or newly diagnosed cardiac disease in pregnancy or in the first 12 months postpartum, is associated with significant serious maternal morbidity and mortality (Australian Institute of Health and Welfare, 2020b;

Knight et al., 2019). CDPP includes a variety of structural heart and aortic diseases, cardiomyopathies, rhythm disorders, ischaemic heart disease, and arterial dissections.

CDPP is under-researched in Australia and internationally. Prevalence estimates range from 1% to 4%, with evidence of increasing prevalence due to delayed childbearing in middle and high-income countries, growing rates of cardio-metabolic risk factors (Regitz-Zagrosek et al., 2018) and increasing numbers of congenital heart disease survivors having children (McClure et al., 2011). Cardiovascular disease has been a leading medical cause of maternal death in Australia for the past five decades, responsible for 14.36% of all maternal deaths between 2009 and 2018 (Australian Institute of Health and Welfare, 2019b). There is significant burden from maternal morbidity with about one-in-four women with cardiac disease during pregnancy requiring hospitalisation (Roos-Hesselink et al., 2013). As maternal mortality reduces morbidity is increasing, yet current maternal morbidity monitoring is affected by inconsistent definitions and criteria, language and monitoring practices (England et al., 2020). The morbidity experienced by women encompasses physical, psychosocial, emotional and functional domains. It is necessary to establish evidence-based information on cardiac presentations, cardiac related complications and women’s experiences.

There is a lack of comprehensive data on the impact of a diagnosis of CDPP has on quality of life, psychosocial and emotional wellbeing and the healthcare experiences of women during pregnancy and the postpartum. A recent meta-synthesis confirmed the paucity of research on the healthcare experiences of women with CDPP and highlighted the need for greater engagement with women and the development of models of care that are responsive to women’s needs, knowledge and desired outcomes (Dawson et al., 2018).

Person-centred care (PCC) is promoted as a model for improved patient outcomes and clinician satisfaction and is based upon the healthcare experiences and needs of patients (Australian Commission on Safety and Quality in Health Care, 2011). PCC protects a person’s dignity, is respectful of, and responsive to, the preferences, needs and values of the individual, and is founded on mutual trust and understanding between care-giver and recipient (Australian Commission on Safety and Quality in Health Care, 2011; Institute of Medicine, 2001).

This study explores the healthcare experiences of women who had CDPP or the first 12 months postpartum in Australia, contributing to the knowledge base for developing guidelines and continuity of care frameworks, resources and PCC, thereby improving women's healthcare experiences and outcomes.

4.4 Methods

4.4.1 Study design

A qualitative study was designed to examine women's experiences of CDPP, privilege women's voices, increase knowledge, and improve clinical care and quality of life. Qualitative research focuses on the way people make sense of, and the meanings they ascribe to, their experiences and the world in which they live (Denzin & Lincoln, 2011). A phenomenological perspective is adopted as is fitting for areas with little existing knowledge, and focuses on the commonality of subjective, lived experiences of a phenomenon within a particular group (Creswell, 2013). The concept of the study was discussed with clinical and community groups from the NSW Heart Foundation. Ethics approval was granted by the University of Technology Sydney's *Human Research Ethics Committee (ETH19-3372)*.

4.4.2 Participants and procedure

Criterion-based purposive sampling was used to engage women who had a diagnosis of CDPP and were willing to participate in an in-depth interview (Palys, 2008). Eligibility criteria specified mothers who have been diagnosed with cardiac disease prior to, during pregnancy or up to 1-year post-partum, living in Australia and who give birth to one or multiple babies beyond 20 weeks, gestation or 400gm or greater birthweight. Women required adequate English fluency to participate in the interview.

The population we sought to interview was both ill-defined and hard-to-reach due to a lack of prevalence data, it involved rare and uncommon conditions, limited registries and disease-based support groups and to our knowledge no support groups specifically for CDPP (Wozney et al., 2019). Online recruitment has been shown to be effective for recruitment for hard-to-reach groups (Whitaker et al., 2017), therefore we posted recruitment notices on the Facebook pages and groups of consenting cardiac groups and organisation, as well as via invitations distributed by cardiac support groups to members' emails and or group newsletters. Thirty-three women responded of which 25 women met the inclusion criteria and agreed to proceed with an interview. Recruitment continued until we had adequate depth and breadth of data to sufficiently describe and analyse the participants' experiences and answer our research question (Braun & Clarke, 2021b).

Most women lived in metropolitan areas, and of the four that lived in regional or rural areas, two transferred to metropolitan hospitals for care during their pregnancy or postpartum event. Fifteen women (60%) had tertiary level education, 7 (28%) had trade level and 3 (12%) had high school education. Their median age at interview was 39 years (range: 28-59). Participant characteristics are outlined in Appendix 1.

4.4.3 Data collection

Semi-structured interviews were used because they are an established qualitative approach when exploring topics about which little is known, focus on the issues that are meaningful for the participant, and allow for diverse perceptions to be expressed (Cridland et al., 2015). An interview guide was developed and data were collected via individual interviews conducted by phone. Interviews were conducted by a single interviewer (JH), took between 24 and 90 minutes and with the women's permission interviews were audio-recorded or hand-transcribed verbatim, including notable non-verbal responses such as crying or laughing. Personal details including names and addresses were not recorded with the study data. Information was re-identifiable only to the interviewer.

4.4.4 Analysis

Inductive reflexive thematic analysis was used as it is flexible and responsive when unexplored phenomena are described; allowed for nuanced theme development; facilitated the coding and organisation of a large and complex data set; and it is able to highlight similarities and differences across the data set (Braun & Clarke, 2021a; Byrne, 2022). Informed by the six stages of analysis outlined by Braun and Clarke (Braun & Clarke, 2006, 2021a) (familiarisation, code generation, theme development, reviewing and refining themes, defining themes and report writing) data coding and preliminary theme generation occurred concurrently with the interview fieldwork and was iterative and responsive to new data and developing patterns.

All study team members listened to the interviews and read the transcripts. JH led the analysis by immersing herself in the data and developing and refining codes and themes and selecting illustrative quotations. The approach to analysis was essentialist/realist (reporting on the experience, meanings and reality of participants) with semantic themes (reflecting the explicit content of the data) (Braun & Clarke, 2006).

4.4.5 Study quality and research team

Each member of the team is a female health care professional with diverse sexual and reproductive health and public health experience. Our shared view is that person-centred care is ethically imperative and requisite for quality healthcare, thus we approached this research believing that understanding and responding to patient experiences is important in ensuring positive outcomes for women and we acknowledge that analysis in part reflects the authors subjective interpretation.

Quality was determined using the guidelines provided by Braun and Clarke (Braun & Clarke, 2021a). In particular, the researchers engaged in ongoing discussion, reflection and development of the codes and themes, exploring individual and shared perspectives on the patterns within and across the women's stories.

4.5 Results

The participants were diverse in age, diagnoses and timing of diagnosis, however they all had rare, potentially life-threatening conditions juxtaposed with the normality of pregnancy and postpartum that transcended differences. Analysis of the data generated five themes: 1) Dismissed: struggling to be heard, 2) Too little, too unclear: in search of information, 3) Winging it: research, education and guidelines, 4) Fragments: care co-ordination and continuity, 5) Making do: fitting into services designed for others.

4.5.1 Dismissed: struggling to be heard

The experience of feeling dismissed by healthcare professionals (HCPs) was the most dominant individual theme in this analysis. Women with all diagnoses reported feeling dismissed in acute and chronic settings, in the community and in hospital, by medical staff, nurses, midwives, ambulance staff and allied health as well as by secretaries and practice managers of medical specialists. The participants suggested that this was due to individual HCPs attitude, gender bias and due to a lack of knowledge about cardiac disease in women especially with pregnancy-related conditions in particular, "*…because it's easy to dismiss a 'healthy' young woman*." (P5)

The women felt unheard when pursuing an initial cardiac diagnosis and when they were experiencing new or ongoing symptoms for an existing diagnosis. Reports of subjective symptoms (e.g. shortness of breath, and chest pain) and objective signs (e.g. ECG changes and elevated troponins) were misattributed to other causes, often without adequate or any investigation. One woman presented with "*a racing heart and cold sweat, aching arm, tight chest pain*," had three positive troponins which the emergency department (ED) doctor concluded were false positives because she was a young female and "*didn't fit a cardiac profile*". (P10)

Women's symptoms were most commonly attributed to as having anxiety, regardless of whether this was exhibited or expressed by the woman. Further, when women were told they had anxiety there was no referral or intervention suggested to support the women.

> *"Do you feel anxious? You might be having an anxiety attack" and I was saying to them, "No... It's not an anxiety attack."* (P23)

The experience of feeling dismissed was iterative. One woman first presented to her general practitioner (GP) in late pregnancy and subsequently had multiple presentations over the following 8 months to both her GP and the ED with chest and jaw pain and "*an odd heart rhythm*" where "*they didn't even examine*" her before she was diagnosed with a myocardial infarction and multiple PSCAD and had emergency bypass surgery. (P6)

One woman reported seeking help for a decade for daily chest pain following her cardiac event. It was not until new research documented the phenomenon that she felt her pain was acknowledged as cardiac, and while she recognised the absence of research at the time, it was the ongoing lack of investigation or offer of support that concerned her.

> *…the GPs, cardiologists, ER staff were all basically saying I was just being hypersensitive and that it was in my mind*. (P16)

There is an overlap of common cardiac, pregnancy and postpartum symptoms, with pregnancy and postpartum causes consistently foregrounded over possible cardiac issues apparently without any investigations. Women were told *"You're tired; you've just had a baby"* (P8) without assessment. Even when women had a known cardiac condition and raised concerns, they at times felt unheard.

> *…even with the breathlessness with me having a known cardiac issue…. I don't remember anyone ever actually just listening to my heart … they're just going to assume that its pregnancy related, not cardiac related.* (P4)

Common cardiac signs and symptoms were also attributed to other conditions such as scoliosis, dehydration, gastroenteritis, or being overweight, again perceived by the women to be a lack of knowledge and a bias issue. A woman who experienced shortness of breath postpartum and later developed jaw pain, chest pressure and palpitations was told by her GP her symptoms were because she was overweight and drank diet cola, and she was advised to lose weight. After two years of ongoing symptoms and multiple presentations to her GP, and once she had lost weight, her GP investigated, leading to a diagnosis of hypertrophic cardiomyopathy. (P8)

A key consequence of women not being heard was delayed diagnoses and the associated preventable morbidity and emotional distress. The women were aware of the dangers inherent in not being heard and taken seriously and they felt "*angry*" and "*disappointed*" that they were "*dismissed*" and "*fobbed off*".

> *To be honest, the way I was going, I think I could have just ended up dying in my bed and people would have still been saying "Oh, it's just the baby".* (P25)

Concerns about prognosis and mortality risk were also under-appreciated and practical and psychological support was not provided. One woman and her partner asked their medical registrar to witness the signing of her Will and was told "*Oh, you won't need this"* despite having just being told that the risk of dying during birth with her cardiac condition was *"50-66%".* (P2)

The women felt their pregnant status or having young babies was often not taken into account in care planning or treatment.

> *They said "Well, you might not get an angiogram for a week or two"; I felt like I was very dismissed. I remember being in tears…snapping at one stage and saying, "Right, and so do these people have a little baby at home that they're breastfeeding?"* (P5)

4.5.2 Too little, too unclear: in search of information

Information was essential for participants to understand their condition, inform decision-making, and to provide re-assurance and confidence; *"It just gives you a little bit of hope that somebody knows what the hell is going on."* (P3)

The women expressed frustration and concern at the lack of information and resources shared with them; they recognised this was in part due to a lack of research but also felt this was not the sole issue. Some felt there was a perceived convention of withholding and gatekeeping information, *"Some of the doctors are like, 'I don't think she needs to see this.'"* (P7) Other times information was oversimplified or alternatively, medical terminology was used and not explained.

> *It was a bit frustrating because I didn't really get it, and everyone kept saying, "Dissection, dissection. Oh, this is the girl with the dissection." I'm like, "What the fuck is a dissection? Can someone just say you've got a tear?"* (P7)

Lack of information created a void which influenced the way the women understood the nature and severity of their condition and this in turn affected their ability to adjust and assume autonomy.

> *I didn't think that what I had was serious…he just sort of gave me a brief description*. (P8)

Women wanted more information and sought it out through obtaining second opinions, online searches and support groups, and this brought both questions and answers.

> *After* [reading] *these other SCAD sufferers, I've thought, 'Oh, I wonder what an LAD is and where my tear was, and I wonder how much damage*?*' I did know that I had an EF of 30, but I don't know what that means.* (P16)

4.5.3 “Winging it”: research, education and guidelines

The women emphasised the need for more research and enhanced clinical training. They understood that their conditions may be rare in pregnancy and postpartum but also that this perception may be inaccurate.

> *I keep getting told how rare this is, but…the more you learn about it everyone’s starting to believe that it’s not that rare, it’s just really underdiagnosed*. (P9)

There was also concern regarding general knowledge, clinical assessment and reasoning skills, including being able to perform common assessments such as ECGs.

> *I go into emergency and some of them have never even heard of what I’ve got…one in 500 people have this, that’s really disappointing that some medical professionals have never heard of it, or they don’t know how to treat it, or they treat it incorrectly.* (P8)

The women in our study perceived a lack of research-informed clinical guidelines in cardiac, pregnancy and postpartum care and expressed frustration, disappointment and at times, apprehension.

> *The answers I was getting weren’t really based on research or on best guidelines or, experience…no-one could ever really give me real answers, and I felt a bit like that was just their gut feelings.* (P19)

The absence of guidelines meant women and their healthcare providers spent additional time seeking information and guidance, often futilely.

> *It was really hard that there wasn’t any information out there, especially when it came to medication and breastfeeding…*[the GP and I] *kept having to ring up the hospital, a lactation information line, and then a pharmacist kept coming back and forwards*. (P10)

Women with pre-existing disease reported a lack of clarity, consistency and communication about the optimal way to manage labour, birth and pain. Some women presented peer-reviewed research on birth for women with their condition to their obstetricians and anaesthetists, however their preferences were not followed, whether they sought a vaginal or a caesarean birth. his was felt to be partly due to a lack of clear research-based guidelines, and that

> *"…having access to their information or their guidelines for all obstetricians or cardiologists around Australia would be really helpful."* (P19)

4.5.4 Fragments: care co-ordination and continuity

Women with CDPP were managed by HCPs from a range of disciplines and specialities. Intra- and inter-discipline co-ordination was seen as inconsistent and was mostly experienced as lacking by the women, and this led to mixed messages, compromised communication, fragmented disrupted care, and distress for women.

Some women proactively sought to enhance care coordination and communication though this was usually unsuccessful. One woman consulted with her cardiologist, obstetrician, obstetric physician and the head of anaesthetics regarding birth, all of whom agreed that an epidural was safe however as she entered theatres she was met by a different anaesthetist who declined to administer an epidural due to "*people with my heart condition having cardiac arrest".* As a result, she had to *"… on the spot decide if I was going to go under a general anaesthetic to have my first child, or possibly risk cardiac arrest".* (P3) She understood the rationale, however was frustrated and distressed by the lack of communication and guidelines, and the futility of her efforts. Another woman tried to act as messenger and negotiator between specialists who she understood had not coordinated care.

> *He* [the anaesthetist] *said that I should have an epidural and caesarean. I said that my cardiologist said that I couldn't have an epidural and he said 'No, you can'. I said I couldn't and then he left.* (P20)

Another participant with pre-existing cardiac disease chose to see a private obstetrician for the continuity of care this would provide. She presented to hospital in early labour as per her obstetrician's advice, however, this plan was not communicated to the hospital and she was sent home which she *"thought that was pretty cavalier".* (P13) She gave birth at term on a weekend with the practice-partner of her obstetrician who had not received any handover because her obstetrician said he did not expect her to give birth that weekend.

> *I don't think it was a good enough reason not to hand the case over to whoever was covering.* (P13)

4.4.5 Making do: fitting into services designed for others

Women described being ‘out of place’ regardless of what ward or service they were in. Those with a known heart condition were an anomaly in a maternity care setting, and pregnant and postpartum women were anomalies in cardiac, emergency and general wards and the women perceived that this contributed to compromised care. Cardiac and rehabilitation services were designed for different populations. Specialist and multidisciplinary care were only available in major metropolitan centres, reducing access and increasing the cost, stress and time required for women to attend. There was little or no service design modification to accommodate pregnant women and women with babies and small children. Specialist obstetric physicians were only available in a few hospitals.

The women recognised that health professionals do not specialise in multiple areas, but at times felt concerned about the care received. In maternity wards “*the staff…don’t have a huge knowledge on the impact of cardiac illness on pregnancy and afterwards.”* (P2) In cardiac wards staff were not used to caring for pregnant and postpartum women;

> “*that was a huge concern. I don’t think that they looked at me as a pregnant woman. I think they looked at me as a cardiac patient”.* (P16)

The lack of knowledge and clinical guidelines in speciality areas was amplified when they were in other wards. Mixed gender wards were particularly difficult for new mothers, such as the following woman admitted after an acute cardiac event postpartum.

> *I was in a shared room with older men with only a curtain between us, I’m having to sit there breast pumping, I’ve got my newborn in there … it was a pretty horrendous experience, the whole thing.* (P12)

Ward management practices appeared to inconsistently reflect baby-friendly hospital practices. Some women were advised that their baby could board in the maternity ward, or that their partner could bring the baby in to her for feeds, presumably not hourly. Not only was the option of having their baby stay with them not always available but women felt scolded for asking. The following woman was in an hospital that had a maternity unit.

> *There had been a whole lot of kerfuffle where they'd said, "It's fine, the baby can stay", because he's fully breastfed, and then the [manager] was, like, "No. He cannot stay. Don't be ridiculous".* (P23)

Cardiac rehabilitation was an area that was consistently reported as inadequate or simply unclear for women with CDPP. Women with the same condition were variously advised to do rehab, avoid it, or that it did not matter either way. Most women felt that rehab as it was offered was not relevant for them. All women who attended rehab noted that it was not designed to accommodate mothers with babies and that the physiotherapist or nurse facilitating the sessions did not always have knowledge of the women's conditions. Some women attended rehab to regain confidence where others wanted specific guidance which was not provided.

> *I felt I just wasted my time. There was nothing about exercise restrictions or what I should be doing. (P10)*

For some women the experience lessened their confidence as they were excluded due to being symptomatic, even though having ongoing symptoms was their 'norm'.

> *I did the cardiac rehab, which I was kicked out of, because I was experiencing pain and they were too scared…I don't think they understood; they had no idea what SCAD was. I had told them that I experienced the pain, whether I sat down, lay down, did exercise, what not. But they weren't comfortable with me maybe dropping dead in their care, I presume. (P16)*

The limited written or digital material available was perceived as irrelevant by most of the women, and *"…the only real support services related to the heart are for people with [atherosclerosis]."* (P13) The lack of resources was especially felt in the absence of a pregnancy and mothering framing, and availability of age and disease-specific support groups.

> *Where does a 25-year-old pregnant woman go who's been diagnosed with a heart condition? There's no real support network for that. (P22)*

The above analysis captures the most compelling and consistent themes generated from the data; however, it is important that this is not the totality of experiences. When women felt heard it made a profound difference: *"You two have been like the first doctors I've really trusted because you've actually listened."* (P1) Some women had supportive, informative and respectful interactions where they didn't *"... feel like I'm going to be belittled by asking."* (P7). Finally, an example of coordinated care was a GP sharing woman's hospital discharge summary with the other GPs in the practice so that everyone was aware of her history and how to manage her care if her treating GP was absent.

4.6 Discussion

This study explored the healthcare experiences of women with CDPP and found their healthcare expectations and needs were not being fully met. The majority of women in our study described a spectrum of largely negative healthcare experiences across multiple presenting cardiac conditions.

Feeling dismissed

The patient experience of being 'dismissed' has been documented in areas of health relevant to women with CDPP including reproductive health, cardiac disease, and rare or medically unclear diagnoses (Galick et al., 2015; Lian & Robson, 2017; Young et al., 2015). Women in our study felt dismissed when presenting at their GP and the ED as well as during pregnancy and during labour, increasing the risk of missed or incorrect diagnoses, morbidity and potentially death. All women experienced delays in diagnosis, and or responding to deterioration in pre-existing cardiac disease, similar to previous findings of it taking 3 to 190 days for women with PPCM to be diagnosed (Patel et al., 2016).

In our study, feeling dismissed affected the women's perceptions of HCPs and in some cases, reduced trust and decreased the likelihood of compliance with treatment or follow-up. Our study is consistent with earlier work that found nearly 40% of women with PPCM experienced symptom dismissal by HCPs and 25% were initially given inaccurate diagnoses, including "new mum anxiety" (Dekker et al., 2016). Analysis of posts on a PPCM online support group similarly reported that women were "brushed off, dismissed and ignored", and incorrectly diagnosed, including with anxiety (Hess & Weinland, 2012).

Person-centred care

The experience of feeling, or being dismissed is counter to the tenets of patient- and PCC. In patient-centred care the patient participates as a respected and autonomous individual, and care is based on individual patient's physical and emotional needs (Kitson et al., 2013). Almost all of the women interviewed described a lack of patient-centred care. PCC is broader and includes the needs and expectations of families and communities and their role in shaping health policy and services and incorporates individuals' personal social determinants of health (World Health Organization, 2010a).

The Institute of Medicine (IOM) published its six dimensions of patient-centredness as essential to providing quality healthcare more than 2 decades ago (Institute of Medicine, 2001). These dimensions are that care needs to: 1) be respectful to the individuals values, preferences, and needs; 2) be coordinated and integrated; 3) provide information, communication, and education; 4) ensure physical comfort; 5) provide emotional support and 6) involve family and friends (Institute of Medicine, 2001). Reflecting on the healthcare experiences of the women in our study it is clear the goals of PCC are yet to be realised, with shortfalls apparent in each of the dimensions.

Women in our study variously felt that they were viewed as 'all baby' or 'all heart' but never as a whole person or mother. They described that their needs both within and beyond the hospital setting were not recognised or responded to. They felt that they were seen as a diagnosis and not a person and did not feel included in decision-making. Pregnant women, women during labour and birth, women with complications during pregnancy, and woman experiencing acute cardiac events as new mothers all felt vulnerable, lacked autonomy and struggled to receive the information they required to engage in their own healthcare decisions. Their needs as a pregnant woman or as a mother were not consistently included in care provided.

Person-centred care and self-advocacy require effective bi-directional communication which was lacking in the majority of women's experiences. Instances where women attempted to self-advocate and navigate the health system were mostly unsuccessful; however, communication and ensuring safe and effective PCC should not be the burden of those with the least power, the patients (Thomas et al., 2021). To successfully self-advocate in health, patients require three attributes: support systems, effective communication with disparate HCPs, and the ability to critique and use health information (Hagan et al., 2017; Waddell et al., 2021). In addition to the heightened vulnerability of having a potentially life-threatening cardiac illness in pregnancy and postpartum, the women in our study had rare conditions, with little information or support available, making it difficult to self-advocate and manage their health experience. Not acknowledging women's knowledge of their bodies, symptoms and needs exists in a socio-political context of devaluing women's knowledge and lived experiences, including of illness (Cole, 2021; Werner & Malterud, 2003).

Continuity of care and care coordination was a priority for the women but was mostly experienced as inconsistent or absent. Continuity of care relates to quality care over time, reflecting the extent to which a series of discrete health care events is experienced as coherent and interconnected, and compatible with the patients' health needs and preferences. Data shows that continuity of care and care coordination is highly valued and is central to PCC; it facilitates trust through ongoing relationships with HCPs and reduces ED visits, hospitalisations and overall health expenditure (Deeny et al., 2017; World Health Organization, 2018).

Women with CDPP often have long-term complex care that requires the involvement and coordination of care from multiple HCPs across different specialities and disciplines. The results of this study reflect those by Hinton and they highlight gaps in coordination and continuity of care, leading to fragmented and inadequate care for women who presented with CDPP (Hinton et al., 2014). At the time of writing there are only two cardiac obstetric clinics in Australia and not all hospitals offer both maternity and cardiac services or have obstetric physicians. Further the women in this study experienced little involvement of anaesthetics services in planning care. This lack of co-located obstetric and cardiac services may jeopardise communication and co-ordination between teams (Knight et al., 2016). Even when women in our study were assertive and proactive, their attempts to coordinate their own care and act as liaison between HCPs of different disciplines failed.

Healthcare professionals

Working within a PCC framework is dynamic, necessarily lacks definitive protocols, and potentially requires a shift in practice for HCPs and patients and a re-imagining of societal perceptions and expectations of HCPs. While PCC is seen as especially important for vulnerable groups, it may be less accessible during serious health events involving rare and uncommon conditions, which may result in less provision of information and shared decision-making, ultimately leading to the individual not receiving PCC, as seen in our study. Clinicians working across specialty areas may feel less confident or competent in some areas and need education, support and guidelines to facilitate best practice, avoid burn out, and tailor management that acknowledges patient experience, especially for long-standing and complex conditions (Eadie & Sheridan, 2017; Pickard & Rogers, 2012).

Healthcare system

It was not our intent in this study to seek fault in HCPs, and for balance, some women described feeling heard, believed and supported and this made a profound difference to their experience of clinical care and the level of trust and safety they felt. However, we note that many of the examples women provided of excellent PCC often involved HCPs going ‘above and beyond’; an obstetrician checking in whilst on leave, the obstetric physician’s negotiated risk assessments to respond to a woman’s request, the midwife staying back hours after her shift ended to provide continuity during labour, the cardiac nurse drawing diagrams at 3am to ensure the woman understood her diagnosis, the GP spending additional time trying to find elusive answers when trying to support the woman’s desire to continue breastfeeding. These examples highlight good practice but the most critical feature is that these examples are of HCPs providing care that is not integrated into regular care, and not structurally or financially supported within the healthcare system. In presenting the six dimensions of PCC the IOM identified the need to build organisations and systems that support change (Institute of Medicine, 2001). PCC encompasses more than clinical interactions and we cannot rely on the professionalism, empathy and excellence of individuals to provide PCC *despite* the system within which they work. We need a healthcare system that carries the burden of implementing PCC and enables HCPs to deliver excellent care. The findings of this study add to recent work exploring patient and HCP identified outcome measures for CDPP, and strategies to implement PCC (Hall & D’Souza, 2020; Mitchell et al., 2020; Nyhof et al., 2020).

4.7 Limitations and strengths

This study may be subject to both positive and negative recall bias. The generalisability of our findings is limited to English-speaking patients with no representation of Australian First Nations women or minority ethnicities. More studies are needed to understand specific needs of women with CDPP, including the needs of diverse populations and needs over time.

A strength of this study is that it is the first study exploring women's healthcare experiences across a spectrum of CDPP. This knowledge contributes valuable information to a small body of knowledge on women's experiences and values relating to CDPP. The interviews allowed women to be authentic and share what was of most importance to them. There was an intensity and density of themes, especially regarding being dismissed, lack of clinician and patient knowledge, and the need for PCC.

4.8 Conclusion

Studies on women's healthcare experiences are essential to build patient agency, healthcare knowledge and inform care. This study identified a lack of PCC for women with CDPP. Of concern is that this equally applies across pre-existing and de novo diagnoses, reflecting a lack of responsiveness of the healthcare system to providing fit for purpose healthcare for women with complex chronic disease who are pregnant or new mothers. This study identified a number of areas in which women wanted system improvement, including: treating women with respect by listening to them, multidisciplinary care planning and co-ordination, increased clinician knowledge and competence, and investment in clinical guidelines, research and patient support. There is an opportunity for cardiac and maternity care providers to listen to women about their healthcare needs and build upon their experiences to enhance care for women with CDPP.

4.9 Chapter summary

This chapter answers the first thesis research question and identifies that women's healthcare expectations and needs are not being met. Further, at times, their healthcare experiences exacerbating their distress and mental health outcomes and, in some cases, not being listened to delayed clinical diagnoses that impacted their cardiac condition. These experiences with consistent with the limited international literature and women likewise lost trust in the health care system and healthcare professionals. The health care system did not accommodate their needs as mothers with cardiac conditions and care was experienced as fragmented, and communication was inconsistent. Chapter 5 explores the issues of not being heard in healthcare in detail.

Chapter 5: Is self-advocacy universally achievable for patients? The experiences of Australian women with cardiac disease in pregnancy and postpartum.

5.1 Publication

The results of this section have been published as follows:

Hutchens, J., Frawley, J., & Sullivan, E. A. (2023). Is self-advocacy universally achievable for patients? The experiences of Australian women with cardiac disease in pregnancy and postpartum. *International Journal of Qualitative Studies on Health and Well-being, 18*(1), 2182953.

5.2 Chapter Introduction

The previous chapter identified that women's experience of feeling dismissed by healthcare professionals (HCPs) was the most dominant individual theme. The feeling of being dismissed was iterative, occurred in a variety of clinical settings, by a range of HCPs in different specialities; in short, there was no setting, specialty or discipline that was not identified by the study participants. Patient self-advocacy is valued and promoted however, the findings in Chapter 4 indicate that it may not be readily accessible to all. This chapter examines research question 1 *"What are the healthcare experiences of women who have CDPP?"* through the lenses of self-advocacy and gender, specifically seeking to elaborate on the contexts, impacts, barriers and women's responses to the barriers to self-advocacy.

5.3 Background

Is self-advocacy universally accessible, achievable or safe for patients? Health policymakers, patients, advocacy groups and health professionals advocate for a shift from medically dominant care models to related conceptual models of person-centred care, woman-centred care in maternity services, self-managed care, shared-decision making, and self-advocacy (McCorkle et al., 2011; Timmermans, 2020). A move away from paternalistic communication and disproportionate power relations requires the patient to be engaged (Timmermans, 2020), self-empowered (Wahlin, 2017), able to self-advocate (T. L. Hagan & Donovan, 2013; Thomas et al., 2021), to assume more responsibility, and to be more active in their care and recovery (Lundmark et al., 2016). These requirements highlight the complexity of shifting paradigms.

Patient self-advocacy has been defined as "gaining and using knowledge to assertively communicate and make decisions" (Brashers et al., 1999) and a patient's behaviour and ability to get their needs met in the face of a challenge (Clark & Stovall, 1996; T. Hagan et al., 2017). These definitions infer that self-advocacy means getting one's preferences met, regardless of circumstances; however, effective self-advocacy is grounded in communication more than outcome, and this distinction may be even more important when there is a lack of guidance on management options, and in an emergency such as a cardiac event. Accordingly, this paper adopts a process-rather than an outcome-focused definition of self-advocacy as "representing one's own interests within the health care decision-making process" (Wright et al., 2007 p36).

Research on gender and women's experiences of self-advocating has been conducted in gynaecological and maternal care (Young et al., 2015), and in the management of pain (Kolmes & Boerstler, 2020). Disenfranchised populations, including women with uncommon medical conditions, are more vulnerable and may be less represented within the dominant culture or systems, leading to additional challenges attempting to self-advocate.

The benefits of effective self-advocacy include improved person-centred care and quality of life, and reduced symptom burden and use of preventative health services (Thomas et al., 2021). Research indicates a positive correlation between patient self-advocacy and patient satisfaction (Brashers et al., 2017; Senders et al., 2016). A secondary benefit may come from confirmation of patients' ability to influence care, increasing their confidence to address other areas, potentially reducing inequities and disparities they may encounter within the health care system (Thomas et al., 2021). Lastly, in currently under-researched areas, healthcare professionals (HCPs) and other patients stand to benefit from an improved understanding of patient perspectives.

Cardiac disease in pregnancy and the first year postpartum

This article examines the self-advocacy experiences of women with cardiac disease in pregnancy and the first year postpartum (CDPP). CDPP includes a heterogeneous group of acquired, congenital and genetic conditions, including structural heart and aortic disease, cardiomyopathies, rhythm disorders, ischaemic heart disease, and arterial dissections. Based on a prevalence of 1% to 4%, (Regitz-Zagrosek et al., 2018) there are 1.3 to 5.2 million women affected by CDPP globally, of which 3,150 to 12,600 are Australian women (Australian Institute of Health and Welfare, 2021). Current estimates of prevalence, morbidity and mortality are likely to under-ascertain the disease burden (England et al., 2020; Vijayaraghavan et al., 2014).

There is little data on the healthcare experiences of women with CDPP, including their experiences of self-advocating. Research on the experience of being diagnosed with CDPP describes women losing trust in the health system after having their symptoms dismissed by HCPs, causing significant distress (Dekker et al., 2016; Patel et al., 2016). Other studies examined mental health and CDPP (Liang et al., 2014; Pfeffer et al., 2020) and birth trauma and the experience of being acutely unwell and hospitalised as a mother of a newborn (Power et al., 2015).

Self-advocacy and cardiac disease in pregnancy and postpartum

Women with CDPP have lifelong cardiac conditions which may reduce the quality and length of their lives (Koutrolou-Sotiropoulou et al., 2016; Rosman et al., 2019). CDPP is a time and context-defined chapter; however, cardiac health is not static and as circumstances change, women need to adjust and re-negotiate care and their daily lives. They interact with a range of HCPs over time, each with their own clinical focus, communication and management style, and women are required to establish functional productive relationships with them all, often at times of illness, acuity and distress. The complex management required to promote and protect their physical and mental health places significant demands on women (Asbring & Närvänen, 2004). Further, women with CDPP need to make informed decisions in an environment of little research, limited and at times conflicting guidance, and without the same level of organised support or access to peers as those with more common conditions. It is important to understand women's experiences of self-advocating in this context to inform future education and support services.

The aim of this analysis is to examine the data through the lenses of self-advocacy and gender, specifically seeking to explore and elaborate on the contexts, impacts, barriers and women's responses to the barriers to self-advocacy.

5.4 Methods

5.4.1 Study design

We used in-depth semi-structured interviews to understand women's experiences of CDPP. Qualitative research in the health field provides insight into patient experiences that not only validates their stories but also raises awareness, and makes meaningful change possible (Denzin & Lincoln, 2011). The concept of the study was discussed with clinical and community groups from the NSW Heart Foundation.

Setting

Australian healthcare is underpinned by Medicare, a universal public health and medical insurance scheme funded by taxpayers. Public patients in public hospitals receive free treatment but are unable to choose their doctor. Public outpatient clinics are available; however, specialist services are restricted to major metropolitan hospitals and face resource limitations. Some services are only available in the public system, such as specialist genetic cardiac disease clinics. Private healthcare includes private hospitals and specialist services. Privately insured patients may have access to health fund rebates for attending private cardiologists or obstetricians. At the time of writing, there are two part-time public cardio-obstetrics clinics in Australia, and they do not cater for women diagnosed with cardiac conditions in the first year postpartum. Likewise, obstetric physicians are available in some large public hospitals but not all, and they care for women during pregnancy, not up to a year postpartum.

5.4.2 Participants

The population we sought to interview was hard to reach as it involves uncommon conditions. There is also a lack of services specifically for CDPP, and limited disease-based support groups. Online recruitment has been demonstrated to be effective in accessing hard to reach groups and thus was our main approach (Whitaker et al., 2017; Wozney et al., 2019). Recruitment proceeded via posts on the social media accounts of selected consenting pregnancy and parenting groups and cardiac support groups, and invitations distributed by cardiac support groups to members' emails and or group newsletters. The women were purposively recruited because they are, or have been, mothers with a diagnosis of cardiac disease who were willing to participate in an in-depth interview. Recruitment was from December 2018 to April 2020, when we had adequate data to sufficiently describe and analyse the women's experiences, and answer our research question (Braun & Clarke, 2021b).

Thirty-three women responded to the recruitment posts, two did not meet the inclusion criteria, six were lost to follow-up, and 25 were interviewed. The women had congenital (n=5), genetic (n=9) and acquired (n=12) cardiac disease in pregnancy or the first 12 months postpartum and gave birth in Australia to at least one live-born baby of 20 weeks gestation or 400gm birthweight (noting that one woman had a genetic and a congenital condition). The women had pre-existing diagnoses (n=9; diagnosed from 2 days old to 26 years old), antepartum diagnoses (n=6) and postpartum diagnoses (n=10; diagnosed from 2 weeks to 11 months postpartum). The majority were first-time mothers (n=15), 5 had their cardiac diagnosis associated with the 2nd pregnancy, 4 with their 3rd pregnancy and 1 with her fourth pregnancy. Most women lived in metropolitan areas, and of the four that lived in regional or rural areas, two transferred to metropolitan hospitals for care during their pregnancy or postpartum event. Fifteen women (60%) had tertiary level education, 7 (28%) had trade level and 3 (12%) had high school education. Their median age at interview was 39 years (range: 28-59). The time from their CDPP to the time of interview was median 36 months, mean 5 years 7 months. The women's characteristics are outlined in Appendix A, and their diagnoses are listed in Appendix B.

5.4.3 Data collection

Data were collected using individual semi-structured, in-depth interviews, a recognised method for investigating topics about which little is known. Semi-structured interviews can accommodate diverse perceptions and enable women to share the issues that are meaningful and important to them (Cridland et al., 2015). The interviews were conducted by phone and by a single interviewer (JH). Interviews began with confirmation of informed consent and the collection of basic demographic data. Personal details including names and addresses were not recorded with the study data. Information was re-identifiable only to the interviewer. The interviews took between 24 and 90 minutes and with the women's permission interviews were audio-recorded or hand-transcribed verbatim, including notable non-verbal responses such as crying or laughing.

The lead question of the interview guide was "Can you tell me about your experience?" Further open-ended questions were devised during the interviews in response to the woman's story and where indicated prompts were used to clarify and expand on the story. This style facilitated an open discussion and encouraged the women to direct the narrative of their story, and include feelings, attitudes and reflections in their own words.

5.4.4 Analysis

Interpretive inductive data analysis was performed using the reflexive thematic analysis (RTA) approach by Braun and Clarke (Braun & Clarke, 2006, 2021a). RTA was used as it is theoretically flexible and accessible, positions the researchers' subjectivity as a resource, and allows for thick description, interpretative story-telling and nuanced theme development (Braun & Clarke, 2006, 2019; Gillberg & Jones, 2019).

Informed by the six stages of analysis outlined by Braun and Clarke (Braun & Clarke, 2006, 2021a) (familiarisation, code generation, theme development, reviewing and refining themes, defining themes and report writing), data coding and theme development was organic and responsive to developing patterns. All study team members listened to the interviews and read the transcripts. led the analysis by immersing herself in the data and developing and refining codes and themes by selecting illustrative quotations.

Quality was determined using the guidelines provided by Braun and Clarke (Braun & Clarke, 2021a). In particular, the researchers engaged in ongoing discussion, reflection and development of the codes and themes, exploring individual and shared perspectives on the patterns within and across the women's stories and reflecting on our influence on interpreting and reporting the data.

The researchers are female healthcare professionals with diverse sexual and reproductive health and public health experience. The approach to analysis was broadly informed by feminism, critical theory and social constructionism (understanding the multiplicity of realities which are constructed through our interactions with others, and situated within social structures that determine power and oppression) with latent themes (reflecting the underlying assumptions and meanings of the stories and semantic meanings) (Braun & Clarke, 2006; Creswell & Poth, 2018).

5.4.5 Ethical considerations

This study was approved by the University of Technology Sydney's Human Research Ethics Committee (ETH19-3372), in accordance with the Australian Code for the Responsible Conduct of Research and the National Statement on Ethical Conduct in Human Research. The participants received oral and written information about the aim and procedure thereof and were informed their participation was voluntary and that they could withdraw at any time without specifying any reason. Consent was obtained from all participants and all data were handled in a confidential manner.

5.5 Results

Analysis produced four themes: 1) Silent dream scream, 2) Easier said than done, 3) Crazy-making, and 4) Concentric circles of advocacy. There was not a one-directional linear progression through the themes; instead, their experiences relating to self-advocacy were iterative and varied with circumstances and contexts. Some interactions were during labour and birth, others during the process of receiving a cardiac diagnosis and treatment, and others were during ongoing health care in the community.

5.5.1 Theme 1: Silent dream scream

All the women experienced the loss of voice, or of being silenced, by themselves, their loved ones and or by HCPs. They interacted with a diverse range of HCPs from a range of specialities and sub-specialities and the issues identified are distributed across these.

Women were silent and felt silenced, especially in the early days following diagnosis and during labour and childbirth. Feeling shocked, confused, fearful or in initial denial of their situation, some women were silent and hid their thoughts and feelings from their HCPs.

> *I was shaking in his room. I went down into the car and cried my eyes out…I was shocked. I didn't let on though*. (HCM, 50yrs)

Not wanting to identify with or be stigmatised as someone with a cardiac condition influenced some women to continue varying degrees of self-imposed silence, in one case "*for 8-10 years I even avoided even communicating it*." (PVO, 48yrs)

Some women felt silenced by their families who minimised the significance of their cardiac event and diagnosis, and who rejected advice or concern about potential risks as genetic relatives of the women.

> *We cancelled the ambulance because my husband was saying "you're okay, you're talking, you're okay", as men do. I was like, sure, because I didn't want it to be anything serious either.* (PSCAD, 37yrs)

The women felt they were silenced, ignored, and dismissed by HCPs, some over many years. These instances ranged from a "don't you worry about that" type of response which was perceived as glib in the absence of meaningful discussion, through to feeling their spoken words were silenced and lost in a vacuum of impotence. A woman with lifelong positive cardiac healthcare experiences and who had previously felt that she used her voice and self-advocated successfully, found the situation different during labour and birth. She reported having been advised by her cardiologist and an anaesthetist that they were happy for her to attempt a natural birth without intervention, however, when she presented to the hospital in early labour her cardiologist was not there and was not consulted.

> *So, they rushed an anaesthetist in and gave me an epidural. Basically ordered me to, and I had the epidural and, I mean, you know, you're scared, so you just do what you're told, basically … they did the epidural, I was literally crying, saying that I don't consent to this. You know, and they did it*. (CHD, 32yrs)

Another woman who had worsening dependent oedema, shortness of breath and discomfort, and who was subsequently diagnosed with PPCM, sought an induction initially at 40 weeks before finally being induced at nearly 42 weeks. She reported asking to be induced several times due to her worsening undiagnosed cardiac symptoms, and two failed cervix sweeps, to be told that the hospital practice was that she "*had to be 10 days over*" to be induced.

> *I was begging them, I was like, can you please just induce me, and they refused.* (PPCM, 28yrs)

5.5.2 Theme 2: Easier said than done

The women in our study reported similar challenges self-advocating, regardless of cardiac condition or category, or if their experiences were during pregnancy or postpartum. However, not all women experienced difficulties in all contexts and times. For example, some of the women with pre-existing cardiac disease had previously self-advocated effectively and felt part of decision-making processes; however, when they were pregnant and labouring, that autonomy and control was felt to be absent. This introduced another dimension to their loss of voice; that this new experience was so different to previous experiences and their expectations of the current healthcare encounter. Women had realistic expectations but were still disturbed by the extent of their loss of voice, and control.

> *I didn't expect to have a sense of control because … it's childbirth … if you try and control it, you know, you're going to end up disappointed, but I had absolutely no control over any of it.* (HCM, 50yrs)

For the women interviewed, this perceived lack of autonomy and control was in part due to the medical situation and in part because the women's wishes or input were not incorporated into care planning, and when she sought information, she was at times met with silence. Women with cardiac disease that was pre-existing or diagnosed during pregnancy typically had multiple medical specialists and care was often perceived as uncoordinated. Women attempted to negotiate and liaise, but without any power or authority.

> *It was hard to make decisions mid-labour and hard having to self-advocate about doing what the cardiologist had instructed.* (HCM, 50yrs)

The majority of women had little experience of advocating for themselves in a health context. It usually took enhanced distress to provoke their assertiveness. The following woman had a PSCAD during pregnancy and was separated from her baby immediately after giving birth.

> *But by the next morning … my whole personality changed. I was an absolute raving lunatic ... I was very meek and mild as a patient [but was now] … a tigress trying to find her child.* (PSCAD, 44yrs)

Some women blamed themselves when their health care experience was negative; for not advocating in a system that is not designed for such behaviour, and against socialisation that, despite some changes, is still grounded in deference not challenge or shared decision-making. One woman's husband suggested pushing for a transfer to a larger hospital.

> *I was saying "No, we should just let the system work. You know, the system should work." And now I think "No" I should have said yes*. (PSCAD, 37yrs)

Perceiving that you do not have rights in healthcare and that you are passive recipients of care prevented women from self-advocating.

> *Had I known about the Patient's Charter, I might have known that it was ok to talk to her senior and say, like "is this right, that I should be staying up all night turning this alarm off because something is not right here." I didn't know that I could say that.* (HCM, 50yrs)

5.5.3 Theme 3: Crazy-making

Feeling silenced, and that they had no sense of control, had significant impacts for women, far beyond their cardiac outcomes. When women perceived their concerns were dismissed or invalidated by HCPs, they were fearful of the possible health outcomes but they also started to doubt themselves and question their understanding of their own lived experiences.

> *I was starting to doubt whether I had the pains. And I thought, no, I actually did. I said to [my partner], "Did I actually have the pains?" And he said, "Yes, you had the pains" because I'm thinking oh my God, you know, this dismissiveness.* (PSCAD, 39yrs)

This woman was transferred between hospitals to have an angiogram and *"when they did the handover it was basically 'this is just stress'"*. The angiogram showed that she had had a PSCAD and heart attack, and while she was relieved to have a diagnosis;

> *I just went oh, you bastards … [the angiogram] almost validated that pain that I had. Because I thought "shit, is this in my head?" Am I making this up?* (PSCAD, 39yrs)

Feeling that they were being dismissed and having their lived experiences denied had a pernicious effect, *"It really, really made me feel like I was going insane."* (CHD, 32yrs) Some women described being *"brushed off"* for years before their situation was acknowledged. This caused women to fear death and uncertainty, having a marked effect on their mental health, self-confidence and self-belief.

> *Oh, it was terrible. I think it was worse than everything put together. I felt like they were telling me that I was going crazy. I was so lucid.* (PSCAD, 44yrs)

Women's experiences of feeling silenced and out of control in healthcare interactions were compounded when they sought medical and mental health care to manage these feelings. One woman who had post-traumatic stress disorder (PTSD) and depression following her birth trauma described her experience:

> *I kind of felt like everyone I spoke to except for my GP justified what had happened at the hospital. And that kind of made me feel shit, because it made me feel like I was going crazy ... It was very invalidating, because I mean, it was my lived experience.* (CHD, 32yrs)

5.5.4 Theme 4: Concentric circles of advocacy

In time, women's experiences of advocating involved advocating for themselves, their children, and for some, other women and girls with cardiac disease.

My self

Some women were able to advocate from the outset on issues that they had knowledge of. One woman who had, at that point, little knowledge about her condition, was less able to advocate for her health compared to her clarity about ensuring her newborn went in the ambulance with her when she was transferred to a different hospital: “I said ‘I’m breastfeeding, she comes with me’, and they were like ‘okay’”. Then when she arrived at the second hospital,

> *… they kept saying we may have to send your baby up to paediatrics, won’t be able to stay with you. I said, “well, that’s not happening”.* (PSCAD, 38yrs)

Women who had subsequent pregnancies used their experience and knowledge to self-advocate, negotiate and assume some control: *“The second time I was able to say ‘I don’t want one of those’”* (HCM, 29yrs) and *“This time I told them not to give me drugs of any sort until I came out”* (LQTS, 30yrs). One woman self-advocated during her second labour regarding the recommended medication loading dose for her induction in a way she was unable to with her first birth.

> *“Okay, but I don’t want it”. So my [independent] midwife kind of bargained with them and said, “Why don’t we start it on a half dose? If nothing happens, we can up the dose”. I was like “yes, I’m happy with that.”* (CHD, 32yrs)

This is also an example of women building their advocacy team, including recruiting other HCPs and partners to the role of temporary vessels of her voice when she may be unable to access her own agency; *“I trained him to within an inch of his life; he was … able to advocate if needed.”*

Women developed their agency and advocacy by seeking second opinions, increasing their knowledge, and by being clear about their expectations and what was and was not acceptable. Women also learnt about their rights, including being able to ask for interventions to stop:

> *In Emergency, a doctor put a central line in via the groin but I had to tell him to stop because it was obvious he didn’t know what he was doing. They’re learning but as a patient, you’re also learning your rights.* (HCM, 50yrs)

One woman's strategy to ensure her voice was heard was to keep a logbook of her pulse rate, blood pressure, oxygen saturation, weeping oedema and symptoms such as shortness of breath and orthopnoea. She was knowledgeable about her condition and had previously had her shortness of breath and central cyanosis dismissed by an emergency department resident as due to a heavy menstrual period and not the significant cardiac compromise she was experiencing. Following this and other incidents where she felt she was not heard or assessed accurately, she *"kind of had to take charge of [her] own health"* and aimed to bolster the authority of her voice by keeping a logbook:

> *When I went back to the congenital cardiologist, I had documental proof, saying, "This is what's been going on." And then they listened.* (CHD, 30yrs)

Women's cardiac conditions were uncommon and often rare during pregnancy and the first year postpartum. The women needed to self-advocate to assume some control of their health, in a way they may not have if their condition was well understood.

> *You have to be very knowledgeable about your own condition, because people don't know about it. They've never heard of it ... You've got to be proactive about that. Most of the cardiologists at the hospital probably wouldn't know anything about this condition.* (LQTS, 38yrs)

Women learnt about their cardiac condition in online support groups, which helped them discuss their concerns with their cardiologists.

> *… since I've found this support group, I knew what questions to ask. Before then, I'd been riding the road of the blind. I had no idea what questions to ask. But slowly and surely, after listening to all these other SCAD sufferers, I've thought, "Oh, I wonder what a LAD is and where my tear was, and I wonder how much damage.* (PSCAD, 44yrs)

Being able to self-advocate and assume some sense of autonomy and control also helped women's mental health and quality of life.

> *I'm a bit more proactive, I go in with a list of questions … "Is there anything that you need to know about how I'm feeling in relation to my ongoing health", and they'll say "No. Not really". And, I'll say "Well, have there been any advances in medical research*

> *recently?" The answer is no always. But I continue to ask the questions, because it helps me to keep going, to know that maybe one day they will actually invent a cure for this.* (LQTS, 38yrs)

My child

Mothers advocated for their children to be tested, to be safely breastfed, and if the children had a cardiac condition, for them to be treated according to guidelines. They *"had to run a bit of a squeaky wheel campaign"* (LQTS, 38yrs) to ensure their baby was tested for genetic conditions.

They were insistent when it came to their child's safety; *"Something's not right. You need to go and get someone"* (CHD, 32yrs), and challenging cardiac care for their child; *"No. No. That's not what the recommendations are for this disease."* (HCM, 44yrs) They rejected recommendations to bottle feed for ease and worked with the doctor and pharmacist until they *"… found something that was safe for breastfeeding because I was quite insistent on that"*. (PSCAD, 38yrs)

My community

As women recovered, some added the broader community to their advocacy efforts. A woman who repeatedly implored the ambulance staff to take her to a tertiary referral hospital was instead taken to a small general hospital where she stayed for 48 hours, not under the care of a cardiologist. In this time her PSCAD and MI were undiagnosed and unmanaged, incurring further cardiac damage. Once recovered enough to engage, she provided feedback to the ambulance service. Instead of seeking a formal apology or suggesting performance management for the staff involved she negotiated that they provide further training so that they were more aware of the characteristics of cardiac disease in young women, especially in pregnancy and postpartum, including PSCAD.

Women found their voices and transitioned from being a member of a Facebook support group to moderating and managing the group. Some women also posted their stories on their private social media pages to increase community awareness of cardiac disease in pregnant and postpartum women, and younger women in general which generated discussion and prompted readers to attend to their health differently.

Women found their voice through a range of community and health projects; they undertook fundraising for equipment and research, ran and contributed to awareness campaigns, and were interviewed in local and national media to increase awareness and to advocate for women. They were members of cardiac care reference groups, acted as peer support for other younger women with cardiac disease and ran peer support education. Being able to use their voice increased their confidence and sense of empowerment.

The women responded to the invitation to be interviewed for this study to have their stories heard; they did this for themselves, but a stronger motivation was to advocate for more research and better care for future girls and women.

> *Yes, it was pretty traumatising but it just made me more determined in my work, to not allow that for anyone else.* (CHD, 32yrs)

When asked what motivated her to participate a woman in her mid-20s replied that despite having cardiac conditions;

> *… it's really important for women to still be empowered and have a say in their pregnancy and their labour.* (CHD, 28yrs)

Even if their physical and emotional healing was not complete, they had reached a place where they were using their voice.

5.6 Discussion

This article examined the concepts of voice and self-advocacy in the lived experiences of women who had cardiac disease in pregnancy and the first year postpartum. Women faced multiple and significant barriers to self-advocacy despite being articulate and educated. They reported times when they were hesitant to self-advocate; however, the more pervasive experience was having their efforts to self-advocate dismissed. The difficulties in having their voices heard and responded to constructively had a marked negative effect on their emotional well-being. The barriers the women faced can be understood at an individual, interpersonal, and societal level. The following discussion considers self-advocacy for this population in terms of personal attributes for self-advocacy and broader societal gender perspectives.

Personal attributes for self-advocacy

Both the experience and effectiveness of self-advocacy are mediated by numerous variables including individual traits, past experiences, availability of information, and the HCPs and health system women interact with. The literature on self-advocacy identifies numerous prerequisites and barriers to self-advocacy. In brief, individuals require; 1) Connection: access to, and disposition to utilise support systems; 2) Communication: the ability to communicate effectively with a diverse range of health professionals; and 3) Knowledge: the capacity to access, evaluate and use health information (T. Hagan et al., 2017; Waddell et al., 2021). Assertiveness and "mindful nonadherence" (Brashers et al., 1999) as well as being able to practice self-compassion to buffer any negative consequences of being assertive or seeking alternatives (Ramos Salazar, 2018) are additional criteria. This brief synopsis of personal attributes belies the complexity of self-advocating at all, let alone in an acute health situation such as childbirth or during a cardiac event or a composite of both scenarios.

The women in our study were uniquely vulnerable as they had significant cardiac disease and acute cardiac events while they were pregnant or a new mother. Both the cardiac and the maternal circumstances are challenging and associated with trauma and distress and having both amplified that effect. A few women with pre-existing conditions were able to access specialist care with an obstetric physician or foetal-maternal medicine physician, but for most, care was fragmented as they tried to coordinate their care between subspecialties. Women with new diagnoses postpartum felt untethered, trying to coordinate care between their cardiologist and general practitioner. No-one felt they belonged regardless of where they were. Most women were not referred to rehabilitation or support groups or informed of Facebook support groups, and it took time for them to find connections, especially for rarer conditions. No cardiac support groups were specifically for mothers, consequently their support and connection needs were only partially met. Most of the women described feeling completely wrong-footed and even disoriented in the early stages, feeling at times, profoundly isolated. The shock, distress and trauma, sparse information and the lack of a community of peers from which to draw strength are counter to the required attributes described by T. Hagan et al. (2017) and contribute to the reasons these capable, competent women still had difficulty self-advocating.

Self-advocacy, person-centred care and shared decision-making are interlinked, requiring strong bi-directional communication. It is relevant to reflect on the background of the women in this study; most were tertiary educated, many were in senior roles, four were health care professionals and one was a health manager. All women in this study spoke fluent English and engaged in lengthy in-depth interviews, clearly articulating their stories. Yet they all experienced difficulties in self-advocating when they had cardiac disease in pregnancy and postpartum, typically on multiple occasions. Given this cohort of patients had challenges with self-advocacy, and by extension with person-centred care and shared decision-making, it is probable that others would face greater barriers, including individuals with low literacy and language skills (T. L. Hagan & Donovan, 2013; France Légaré & Witteman, 2013; McCormack et al., 2017).

The efficacy of self-advocating was lowest, and self-silencing and the sense of being silenced were most pronounced during the high acuity situations of labour and acute cardiac events. Our findings were consistent with previous research reporting that in the early stages following severe maternal morbidity some women "…wanted to bide their time and heal and some wanted a voice in their healthcare" (Cram et al., 2019 p63). Thomas et al. (2021) described a constellation of circumstances for women with cancer to be able to self-advocate, including developing personal skills and adjusting their priorities. For women in our study the critical time to self-advocate was in high-acuity situations where there was little or no time to gather information, consult widely, reflect or seek connection.

Once the acute stage had passed, women still faced fundamental challenges in self-advocating. Their conditions were uncommon or rare, and data to inform shared decision-making and efforts to self-advocate was scarce. The majority of women were not attempting to self-advocate for different treatment options or interventions in this knowledge void; rather, their advocacy efforts and goals were often rudimentary. They wanted to be heard. And being heard would facilitate being assessed, diagnosed and treated with the degree of attention and urgency their conditions required. Women wanted to be told what their diagnosis was and to have it explained to them; to be provided with what evidence there was and when there was none, to have the rationale of recommended care explained.

Effective communication is predicated on bi-directional knowledge transfer, to both gain knowledge and build relationships. Silencing, as described by the women in our study as they attempted to describe their symptoms, values and needs represents missed opportunities to provide person-centred care and to add to the knowledge bank and understanding of rare and uncommon conditions. Knowledge is not neutral; what is known, by whom and what value that knowledge has is fundamentally embedded within power relationships, equity and equality (Gillberg & Jones, 2019). Patients may inadvertently contribute to the one-sidedness in knowledge exchange by undervaluing the significance of their expertise in their own body and experience, and underestimating their ability to share knowledge that HCPs "own" (Joseph-Williams et al., 2014). Lastly, while power is constructed as knowledge (Foucault, 2007), it is such only if wielded; if women were not able to self-advocate even in the times when they had objective knowledge, then they remained without power.

Gender and self-advocacy

The imbalance in ownership and valuing of knowledge exists in a socio-political context that diminishes women's knowledge and lived experiences, including of illness (Cole, 2021; Werner & Malterud, 2003). Women's experiences in other settings influence their interactions and ability to self-advocate in the health setting, in particular any previous experiences or expectations of backlash against assertiveness or self-advocacy. Such backlash against women is theorised as retribution for violating gender norms, acting counter to beliefs about proper roles for males and females and disturbing the rightful social order (Rudman et al., 2012; Williams & Tiedens, 2016).

Occupational research indicates that women who self-advocate are viewed as less likeable and not as warm and that women hedge their assertiveness to minimise backlash and maintain a positive perception of themselves. Similarly, some women in our study were motivated to explain that they were normally a "the likeable patient, the good patient"

(Amanatullah & Morris, 2010; Williams & Tiedens, 2016) and "not the kind of woman who complains" (Werner et al., 2004). Women self-advocating with male specialists are subverting social order on multiple dimensions; as women, as patients, as mothers, and possibly as people of perceived lower status. Women may be more able to self-advocate with female specialists who may be more likely to practice patient-centred care.

Silencing and infantilising women are not new. In The Public Voice of Women: Oh do shut-up dear Beard (2014) traces the first Western recorded ownership of speech, knowledge and power in Homer's Odyssey when Telemachus tells his mother, Penelope, to go to her room because "Speech will be the business of men, all men and me most of all, for mine is the power in this household". Gendered silencing can be overt and even violent; however, it can also be subtle and under the guise of paternalistic care. This "benevolent sexism" (Travis et al., 2012) can be seen in our study for example when women asked simple questions about what their diagnosis and treatment plan was and described being dismissed with comments like "don't you worry about any of that".

Gender and cardiac disease

Women are under-represented in cardiac research (Jin et al., 2020; Norris et al., 2020) and when they are included, data may not be sex-disaggregated ((Doull et al., 2010; Lam et al., 2019). Research on cardiac disease and pregnancy and postpartum is also limited. Women with cardiac conditions are under-diagnosed, under-treated and less likely to have interventions and treatment adherent to clinical guidelines (Arora et al., 2015; Bachelet et al., 2021; A. E. Johnson et al., 2018). Women are less likely to be referred to cardiac rehabilitation even though attendance may be associated with a greater reduction in mortality compared with men, noting there is limited research on pregnancy-related cardiac disease (Colbert et al., 2015; Colella et al., 2015; Sawan et al., 2022). Consequently, women with cardiac disease have worse morbidity and mortality outcomes (Alabas et al., 2017; Butters et al., 2021).

Research demonstrates that women's cardiac outcomes are poorer if there is a physician-patient gender discordance (Lau et al., 2021). In contrast, Sun et al. (2021) found no gender discordance difference in length of stay or mortality but that female patients with a female surgeon (or a female surgeon and anaesthetist dyad) had shorter lengths of stay, confirming findings by Greenwood et al. (2018) that male physicians treating female patients was associated with poorer outcomes, not gender discordance per se. Education is recommended for healthcare professionals and for women to be empowered to self-advocate, however it is critical to ensure women do not experience negative fall-out if their efforts in self-advocating develop faster than education and cultural changes within which they seek care (Stehli et al., 2021). Further, recent research highlights the functions and benefits of a cardio-obstetric, multi-disciplinary team approach to cardiac disease in pregnancy, which may reduce some of the issues faced by the women in our study (Easter et al., 2020; Magun et al., 2020; O'Kelly et al., 2021).

Gender and reproductive health

Similar to women with cardiac conditions, women with reproductive issues experience being dismissed, under-diagnosed and misdiagnosed (Osborn et al., 2020). Gynaecological symptoms that are not readily diagnosable may be attributed to psychiatric disorders (Jones, 2015) and women's knowledge of their own bodies again being taken as subordinate to the authority of doctors (Lupton, 2012; Young et al., 2020). Women in our study consistently had their expertise in their bodies undervalued, whether it was about existing conditions or in describing symptoms of de novo conditions. In place of accepting the primacy of their bodily knowledge they were asked if they were an "anxious type". The tendency to defer to sociohistorical constructions of women and their bodies (including hysteria discourse) may be amplified in situations of medical uncertainty, and this may be relevant in the case of young women with cardiac disease in pregnancy and postpartum (Lian & Robson, 2017; Young et al., 2019).

The potential role of gender in the experiences of self-advocating in our study is significant but it is also noteworthy that perceptions of negative interactions were not universal and that some women described supportive care and being listened to. While awareness of gender bias and discrepancies in health care and research is growing, to date research has focused on the object of bias, women, and little has addressed the subject, the health care professionals (Alcalde-Rubio et al., 2020). Specifically, a recent scoping review identified that the majority of research on gender bias was related to cardiovascular disease and that the focus was on strategies to increase adherence to existing guidelines to standardise healthcare (Alcalde-Rubio et al., 2020). The women in our study employed multiple approaches in attempting to self-advocate which is in line with findings by Kolmes and Boerstler (2020). Similarly, Maslen and Lupton (2018) found that women were resourceful, active, and creative in accessing and using online information to enhance their experiences in clinical consultations. Notwithstanding the recognition of the impact of societal gender-based barriers, there is a need to undertake further research and develop strategies to facilitate self-advocacy.

In all contexts, trust influences communication and self-advocacy and is essential for safe patient care (Chandra et al., 2018; Frey, 2011). Most research on trust has focused on patients trusting the physician, which is clearly important, but also reflects the paternalism discussed and the markedly unequal valuing of the HCP's knowledge and experience over that of the patient (Grob et al., 2019; Thom et al., 2011). That patient's experiential knowledge is viewed as lacking credibility is both flawed and restricts the ability to gather clinical knowledge and establish trust and rapport (Frey, 2011; Nizzi, 2021). Patients will never be able to effectively self-advocate if HCPs don't trust them, regardless of the patient's self-advocacy credentials.

Any focus on and development of patients' ability to self-advocate needs to be mirrored by action by HCPs and health care systems, and needs to recognise the broader socio-political context. Effective self-advocacy is associated with positive outcomes; however, the burden of communication and person-centred care cannot rest with the party with the least power, the patients (Thomas et al., 2021). Further, only focusing on self-advocacy and self-empowerment of the individual does so at the cost of ignoring systemic barriers (Coddington, 2017). Encouraging patients to self-advocate with HCPs and healthcare systems that do not meet their self-advocacy constructively and positively risks the diminution of trust, weakening of relationships, emotional fallout, passive or active disengagement and resistance to pursue recommended treatment (Schinkel et al., 2019). Whether it is in an acute or chronic health situation, it is exhausting to constantly convince others of your credibility (Werner & Malterud, 2003).

5.7 Limitations and strengths

Methodological limitations include that the majority of interviewees responded to social media recruitment strategies and thus women not using social media are unlikely to be included in this study. The study may be subject to recall bias, both positive and negative, as time has passed since the experiences discussed. Further, it is not representative of a diversity of women and thus the critical issue of intersectional amplification of barriers has not been examined. We argue that the vulnerability and barriers experienced by women with CDPP are significant and complex, leading to psychological distress and delayed diagnosis and treatment. This is in the context of the women in our study being white, educated and able-bodied. How does one self-advocate as a person who has experienced, potentially lifelong, personal and systemic racism, who is differently abled, has a different social status, religion, or sexuality? The findings of research must be built upon in different contexts to better address the additional complexity of intersectional barriers and influences (Crenshaw, 1991).

We also recognise that there is no “one” voice and this paper does not and cannot speak to every woman’s experience. Our sample included women with a range of diagnoses and this heterogeneity means there are small numbers in each category. However, to our knowledge, this is the first study exploring women’s experiences of self-advocating across a spectrum of CDPP, and this allowed for the inclusion of women with rare diseases who otherwise may not be included in research due to the low prevalence of these conditions.

5.8 Conclusion

The experience of having cardiac disease in pregnancy and the first year postpartum can be distressing, disorienting and isolating. Regardless of women’s personal attributes, knowledge and experience, self-advocating for their health is complex and difficult. The inability of women to have their voices heard had negative cardiac and psychological outcomes. Women were resilient and resourceful in finding their voices and through digital media to find and build a community around cardiac disease in pregnancy. However, person-centred care places a requirement on health systems to provide an adequately resourced and culturally safe environment where healthcare professionals are supported to provide person-centred care.

5.9 Chapter summary

This chapter builds on the findings of Chapter 4 in answering the first thesis research question. Regardless of women’s individual attributes, knowledge and experience, self-advocating for their health was complex and difficult, and had negative cardiac and psychological outcomes. Despite the significant barriers to self-advocating, the women were resilient and ultimately developed strategies to be heard and to advocate on their own behalf and that of other women. Findings from this research can be used to identify ways to support women to self-advocate, and to provide adequately resourced and culturally safe environment to enable healthcare professionals to provide person-centred care. The following chapter examines the mental health outcomes and sense of isolation for women with CDPP.

Chapter 6: Cardiac disease in pregnancy and the first year postpartum: a story of mental health, identity and connection.

6.1 Publication

The results of this section have been published as follows:

Hutchens, J., Frawley, J., & Sullivan, E. A. (2022). Cardiac disease in pregnancy and the first year postpartum: a story of mental health, identity and connection. *BMC Pregnancy and Childbirth*, *22*(1), 1-13.

6.2 Chapter introduction

This chapter examines the mental health of women with cardiac disease in pregnancy and the first twelve months postpartum (CDPP), answering the thesis research Question 2 *"What is the impact of having CDPP on women's mental health?"* Chapter 4 described women's healthcare experiences and Chapter 5 provided in-depth analysis of a key aspect of those experiences, that of feeling dismissed and struggling to effectively advocate for themselves in the health space. One aspect of those experiences was feeling anxious, depressed and traumatised, important outcomes in themselves, but additionally relevant due to the bidirectional relationship of negative mental health states and poor cardiac outcomes.

6.3 Background

Cardiac disease is a leading cause of maternal morbidity and mortality (Regitz-Zagrosek et al., 2018; Roos-Hesselink et al., 2013). The term 'cardiac disease in pregnancy and postpartum' (CDPP) describes a heterogeneous group of genetic, congenital and acquired conditions, including structural heart and aortic disease, cardiomyopathies, rhythm disorders, ischaemic heart disease, and arterial dissections. These conditions are pre-existing, or diagnosed in pregnancy or the postpartum period.

Individual cardiac diseases in pregnancy may be rare; however, international prevalence estimates for combined CDPP are 1% to 4% with evidence of increasing prevalence (McClure et al., 2011; Regitz-Zagrosek et al., 2018). In Australia, the overall maternal mortality rate is low and stable; for 2015-2017 cardiovascular disease was the second most common cause of death, accounting for 13.6% of deaths (Australian Institute of Health and Welfare, 2020b). CDPP is associated with serious maternal morbidity across physical, psychosocial and functional domains. An estimated one in four women with cardiac disease during pregnancy requires hospitalisation (Roos-Hesselink et al., 2013) and for each maternal cardiac death nearly eight women have severe morbidity (Huisman et al., 2013).

Current estimates of prevalance and mortality, and the scale and nature of morbidity, are likely to under-ascertain the disease burden. Morbidity monitoring is affected by inconsistent definitions and criteria, language and monitoring practices (England et al., 2020; Malhamé et al., 2020). Newly defined conditions may not be captured in earlier research, and diagnosis may require a level of imaging equipment and expertise not available at all sites. Additionally, both mortality and morbidity studies inconsistently include women diagnosed in the late and very late postpartum periods (Vijayaraghavan et al., 2014), women managed outside the hospital system, and women with milder symptoms who go undiagnosed. This limits our understanding of the breadth of disease characteristics.

Based on a prevalence of 1% to 4%, there are 1.3 to 5.2 million women affected annually by CDPP globally, of which 3,150 to 12,600 are Australian. The lack of research exploring the experiences of this considerable cohort of women, is in and of itself, a reason for further inquiry.

There is a lack of comprehensive data on the experiences of women with CDPP. In addition, only a limited number of studies have reviewed the impact of CDPP on activities of daily life, mental health, quality of life, relationships, loss of income, and the effects of the persistent risk of worsening cardiac health and premature death. A recent meta-synthesis of 11 studies that examined the experiences of women with existing or acquired CDPP who were or had been pregnant, or who had contemplated pregnancy confirmed the paucity of research about women's experiences and highlighted the need for women to share their stories (Dawson et al., 2018). These stories could inform the development of models of care that are responsive to women’s needs, values, knowledge and desired outcomes.

Women with CDPP are situated at the intersection of several and varied medical and psychological conditions, each potentially bringing significant morbidity. They are at risk of worsening cardiac disease, chronic illness, mental illness, trauma and death. Their pregnancy, labour, birth and postpartum recovery may be complicated. This compounded risk exposure may lead to significant and long-term negative outcomes. It is critical to understand women’s experiences to develop and provide evidence-based guidelines that meet their needs in the acute hospital setting and after discharge to the community.

The aim of the study is to explore in-depth the lived experiences of Australian women with cardiac disease in pregnancy and the first year postpartum.

6.4 Methods

6.4.1 Study design

A qualitative study design using in-depth semi-structured interviews was designed to achieve the aim of understanding women’s experiences of cardiac disease in pregnancy and the first year postpartum. Qualitative health research provides an insight into patient experiences that not only validates their stories but also raises awareness, and makes meaningful change possible (Taylor & Francis, 2013). The concept of the study was discussed with clinical and community groups from the NSW Heart Foundation

6.4.2 Participants

Women with CDPP who gave birth in Australia to at least one live born baby of 20 weeks’ gestation or 400gm birthweight were invited to participate. CDPP is defined as pre-existing or newly diagnosed cardiac disease in pregnancy or in the first 12 months postpartum. Women required adequate English fluency to participate in the interview and women whose primary diagnosis was hypertension, pre/eclampsia or thromboembolic disorders were excluded from the study.

Recruitment was via advertisements posted on the social media of selected consenting pregnancy and parenting groups and cardiac support groups, and via direct and indirect invitations distributed by cardiac support groups to members' emails and or group newsletters. Participants were purposively recruited because they are, or have been, mothers with a diagnosis of cardiac disease who were willing to participate in an in-depth interview. Recruitment continued until we had adequate depth and breadth of data to sufficiently describe and analyse the participants' experiences and answer our research question (Braun & Clarke, 2021b). Recruitment was from December 2018 to April 2020.

6.4.3 Data collection

We used semi-structured, in-depth interviews which is a recognised qualitative approach for investigating topics about which little is known and it privileges the issues that are meaningful for the participant and can accommodate diverse perceptions (Cridland et al., 2015). Individual interviews conducted by phone and were conducted by a single interviewer (JH). Interviews began with confirmation of informed consent and the collection of basic demographic data. Participants were asked to choose a pseudonym to protect their identity. The interviews took between 24 and 90 minutes and with the women's permission interviews were audio-recorded or hand-transcribed verbatim, including notable non-verbal responses such as crying or laughing.

An interview guide was developed with the lead question *"Can you tell me about your experience?"* Additional open-ended questions were formulated during the interviews in response to the participant's story and where appropriate, prompts were used to clarify and expand on the account provided. This approach enabled participants to share any information they wanted to, including feelings, attitudes and reflections in their own words, and to provide a space that encouraged them to direct the narrative of their story.

6.4.4 Data management and analysis

Interpretive inductive thematic analysis was used as it is flexible and responsive when unexplored phenomena are described; facilitated the coding and organisation of a large and complex data set and nuanced theme generation; and was suitable for rich narrative description (Braun & Clarke, 2021a; Byrne, 2022). Informed by the six stages of analysis outlined by Braun and Clarke (Braun & Clarke, 2006, 2021a) (familiarisation, code generation, theme development, reviewing and refining themes, defining themes and report writing) data coding and preliminary theme generation occurred concurrently with the interview fieldwork and was iterative and responsive to new data and developing patterns.

All study team members listened to the interviews and read the transcripts. JH led the analysis by immersing herself in the data and developing and refining codes and themes and selecting illustrative quotations. The approach to analysis was broadly informed by critical theory and social constructionism with latent themes (reflecting the underlying assumptions and meanings of the stories and semantic meanings) (Braun & Clarke, 2006; Creswell & Poth, 2018).

6.4.5 Ethical considerations

Written or recorded verbal informed consent was obtained from all participants. Ethics approval was granted by the University of Technology Sydney's Human Research Ethics Committee (ETH19-3372).

6.5 Results

We interviewed twenty-five women of different ages who had a variety of diagnoses and timing of diagnosis, but who all had a rare, potentially life-threatening cardiac condition whilst pregnant or postpartum. The majority lived in metropolitan areas, and of the four who lived in regional or rural areas, two transferred to metropolitan hospitals for care during their pregnancy or postpartum event. More than half had tertiary level education (60%), seven (28%) had trade level and three (12%) had high school education. Their median age at interview was 39 years (range: 28-59) and age at time of diagnosis ranged from 2 days to 46 years old. Their cardiac diagnoses were categorised as congenital (n=5), genetic (n=9) and acquired (n=12) conditions, with one woman having both genetic and congenital diagnoses. Timing of diagnosis was prior to pregnancy (n=9; diagnosed from 2 days old to 26 years old), antepartum (n=6) and postpartum (n=10; diagnosed from 2 weeks to 11 months postpartum). Most were first-time mothers (n=15), five had their cardiac diagnosis associated with the 2nd birth, four with their 3rd birth and one with her fourth birth. Six women had subsequent pregnancies. There were no stillbirths or neonatal deaths for the pregnancies discussed. Participant diagnoses are provided in Appendix 1.

The interviews provided complex and varied data. Analysis produced three major themes: 1) Ground zero; index events and their emotional and psychological impact; 2) Self-perception, identity and worthiness; 3) On the road alone; isolation and connection. The themes and sub-themes are described as discrete entities, however they overlapped, and interacted with each other. Movement between themes and stages was fluid and iterative, and not a linear trajectory from illness to health.

6.5.1 Theme 1: Ground zero: index events and their emotional and psychological impact

Women across the spectrum of diagnoses described traumatising events, feeling disempowered, experiencing psychological distress and struggling to recover emotionally.

Shock and anger

Women were shocked and distressed by their clinical status and by the way it was communicated to them. One woman attended a routine cardiac review feeling well and unchanged in her health and was unexpectedly told:

> *"Your heart is so bad you'll need a transplant at some point" … oh, and then he said, "Hmmm, that's if you get a heart."* (W20)

Some women felt angry that they had a serious cardiac condition that imposed significant restrictions on them, especially given they had healthy lifestyles and no traditional cardiac risk factors: *"It just felt really unfair and I just felt really sad".* (W9). The frustration of not being able to do what they once did merged the anger and the anxiety, *"I was so angry… and I've still got the demons (anxiety)."* (W7). Women were also angry and "pissed off" (W25) that their condition or deterioration was not diagnosed earlier despite multiple presentations to doctors and emergency departments, where they were repeatedly dismissed.

Anxiety and post-traumatic stress disorder

Anxiety was common and for some women symptoms of anxiety were pervasive and unrelenting. Triggers were varied, including concerns regarding access to care, *"…anxiety-wise … it's always in the back of your mind that if something does happen, then we are kind of screwed"* (W1), and a lack of trust in the health professionals; *"I was also fairly panicked thinking, 'I don't feel confident you know what's going on'".* (W23).

Fear and anxiety were also in direct response to cardiac events or deterioration.

> *I just felt everything fading away. And I was really, really scared. I got again that impending sense of doom, I just, I thought, I'm dying, I'm dying.* (W25).

Women were alarmed that they nearly died; that they unknowingly had a condition that *"could have killed [them] at any point"* (W12) and that when they 'Googled' their condition the main information accessed exacerbated their fears, *"Oh God, you just think you're going to die"*. (W25).

Women with persistent cardiac symptoms, especially if they were the same as for their major cardiac event, had a seemingly unremitting trigger for anxiety.

> *[Pain]… several times a day feeling like, "Oh, is this it?" [worrying they'll] drop dead every five, ten times we have the pain a day.* (W16).

They described feeling *"stunted by fear and anxiety*" (W12), and not attending rehabilitation or exercising due to fear of triggering further cardiac damage.

> *I was scared out of my wits, and I got to the stage where I couldn't push the pram for fear that if I had [another] heart attack, the pram would be pushed under traffic or something. I wasn't only fearful for myself; it was more for the baby.* (W16)

Women with genetic conditions had the additional worry about passing on their conditions, *"the anxiety that I felt around thinking that my son had it was so overwhelming."* (W12). Several women had persistent intrusive thoughts from their *"very traumatic experience*". (W23).

> *You've just got these constant daily reminders … I feel like that's all I'm ever thinking about. So unless I'm distracted I find it quite hard to be positive now. And yeah, it's definitely taken a toll.* (W9).

Trauma was not necessarily an isolated incident, instead *"…there's sustained trauma in it. There's trauma from the start, and then there's just trauma*", (W12) and a number of the women required treatment for post-traumatic stress disorder (PTSD). Typically, women experienced prolonged or repeated distress and felt unsupported, which compounded prior experiences, creating multiple points of harm. For example, one woman who felt physically weak and dizzy, was traumatised and distressed by her birth experience, and whose baby was in the neonatal intensive care unit (NICU) asked for help to be taken to the NICU after they called for her and was told:

> *"Oh, no, no. Just go down there and if you feel like you're going to pass out, sit down on the floor and just yell out and someone will hear you."* (W14).

The fear, trauma and *"horrid postnatal depression"* she experienced made her determined to not return to the hospital where it occurred however, she was transferred there when ill a number of years later.

> *"I'm not going back to that major hospital because I'm absolutely traumatised. I never want to go there ever again for any reason, ever," and I have been there since, and I had an absolute panic attack … They opened the door of the lift … right next to NICU, and I lost my mind. I absolutely lost it, I was crying and shaking. It was … a trauma response.* (W14).

Multifaceted, compounded trauma, grief and depression

Women 'lost months' where they were on emotional and cognitive auto-pilot. It took time to recognise the level of anxiety, terror and depression that they had been living with. For some women it wasn't until weeks, months or years later that they experienced generalised or postnatal depression or when *"…it all sort of came unravelling*". (W21) For others and their families, the emotional toll of their experiences did not come into focus until their physical health stabilised.

> *…as I started to get a little bit physically better was probably when …mentally and emotionally things started to fall apart for me.* (W9).

The negative impact on their mental health was long-term for some women and for their families.

> *I think it is only years later that the toll has become very evident, for the whole family, in terms of mental health. I think the whole family has struggled with it … That's the fallout really.* (W20).

The experiences of trauma, grief, anxiety and depression were layered and the impact of the complex array of losses was at times exacerbated by the communication style of health professionals. Most women were advised to avoid future pregnancies; the grief and distress felt in response to this advice was compounded by their loss of autonomy in decision-making about such a fundamental issue in their lives.

> *[I see the Dr] …two minutes each day doing rounds, and he goes to me "Oh, that means no more babies too now". It was just such a blasé comment, and then he left. That was sort of a bit of a devastating blow at the time too because I would have liked to have made the decision … I took that really hard*. (W10).

They grieved previous pregnancy loss and loss of time with their newborn and older children as they struggled in the acute aftermath of their experiences and because they were restricted in what they were able to do in recovery.

> *I could not believe that it wasn't enough that I'd lost a child, that I had to go through [this] shit on top of it.* (W7).

Recognition, support and healing

Following their cardiac event or birthing experience women felt alone, isolated, and that their mental health needs were almost exclusively not recognised.

> *You know, year after year, and not getting any help. No-one saying, "Well, maybe you should talk to your doctor about depression."* (W16).

All but one woman who had counselling, sought it out themselves. Psychological recovery has been of an uneven pace and trajectory and was informed by their individual histories, situations and support. Ongoing symptoms and undesirable cardiac outcomes complicate efforts to heal emotionally and for some women *"the hardest part of recovery is the emotional recovery"* (W7) which was invisible and more difficult and protracted than physical healing.

> *I have really struggled with it – it's been a year and I'm still kind of, you know, grappling with all that sort of stuff*. (W9).

> *… my heart's healed; I still have the psychological healing to do.* (W15).

Recovery from the psychological impact of their experiences required that they were able to carve out some space and time to care for themselves, to centre their mental health. Women consulted with psychologists and counsellors, incorporated meditation practice, and connected with other women with similar experiences.

Stigma surrounding mental health, a self-perception of not needing help, and a tendency to put other people's needs first influenced women' reluctance to seek help. Several participants recommended that mental healthcare be incorporated into routine post-cardiac care and clinical guidelines to overcome barriers to access.

> *You put yourself last. If you have something that's told you're supposed to go do [de-briefing, counselling], then you might make the time for it*. (W15)

The women identified that they required specialised psychological care and that *"medical professionals who deal with physical health … just don't seem to be very aware of the psychological aspect."* (W13).

> *So, physical care is one thing, but I think anything around mental health in it is just critically important. Because that's the thing that's either going to get you through the rest of your life or not, or hold you in a space that you just won't be able to move from …this experience for me wasn't very long ago, and I don't feel I was offered nearly enough assistance around that.* (W12).

Connecting with peers through support groups or a dedicated peer support program was also identified as being valuable.

> *Talking to someone who's the same age who's done the same kind of things, or is at the same life level with the same conditions, is really helpful*. (W1).

6.5.2 Theme 2: Self-perception, identity and worthiness

Becoming a mother and having a major cardiac event brought changes to women's self-perception, identity and understanding of what their lives will be.

Was it me? This is not me.

In the immediate period after a shock it is common to question if you were responsible or somehow contributed, as some women in this study did, *"all of a sudden I'm thinking, God, I ate too many hot chips, you know, I didn't exercise enough*" (W15). However, this extended to self-deprecation, *"I'm just so tired; it's just 'cause I'm old and fat"* (W2) and blaming themselves for failing to detect changes in their condition that their specialists hadn't, including pre-eclampsia *"…it's sort of a bit of ignorance on my behalf too…it's my baby*. (W21).

Women with pre-existing disease were well before their pregnancies and women with new diagnoses were well before their cardiac event, which made it hard to identify with having an acute event or new chronic health issue.

> *It's when you're very healthy and then you're told that you're not healthy … I didn't feel sick, I didn't look sick, I didn't act sick, so it was really challenging for me to comprehend that*. (W22).

Not identifying with a condition, especially once they felt well again, contributed to some women not wanting to join a support group *that "… makes it more defining than what I want it to be"*. (W17).

Some women identified as being *"pretty strong and resilient"* (W5) and of having a *"level of emotional intelligence [that] is quite high"* (W2); this was both their nature plus they had developed skills and resilience through previous experiences.

Who am I now?

Women described the uninvited dismantling of existing self-identity as a consequence of their experiences and the need to re-shape their idea of who they were as they moved ahead.

> *"I was very very active, I was the manager of several [sites]. I've been a very keen athletic, sporty kind of person, so I was very, very healthy before. So it was a real lesson to have to change my whole being, change my whole lifestyle."* (W16).

> *When you're diagnosed with something like this that you've always had, you're sort of left feeling a bit empty and weird. You have to just keep going now, but you're a different person ... everything's different.* (W12).

(Un)Deserving and downplaying

Women delayed seeking care or calling an ambulance, including mid-heart attack, because they thought someone else may be more deserving of that care or service. As they found their voices in recovery, several wanted to stress that women are worthy of healthcare and that they need to call the ambulance, to seek help.

> *Particularly as mums, we always put ourselves last and we think we're wasting other people's time. That's why I refused the ambulance because I thought … someone could die because they're with me, and you know, I'm not important and I'll – I'll be fine, I'm a fighter, I'm resilient, you know, I deal with things. And I think a lot of women are like that. We always put ourselves last, and it's just so important not to do that.* (W5).

In addition to the idea of being worthy of emergency medical help, women's sense of worthiness was also demonstrated in comments about the impact on their families and not wanting to be a burden on them, *"I feel like everyone's already helping us out so much."* (W23).

Other times the question of worthiness was external, for example when the focus was on their partners and not them, making them feel disregarded and invisible.

> *"Oh, my God, your husband's so amazing. He's doing these great things with the kids." I'm like, "Well, yes, I get it, but I nearly died here and I've got no choice and what about me hey?"* (W7).

The women interviewed downplayed their medical condition or concerns and this was associated with fear and anxiety, guilt, regret, not wanting to upset or be a burden on their families, reluctance to take up space, the sense that they had somehow caused the condition and that they have given it to their children.

6.5.3 Theme 3: On the road alone; isolation and connection

Isolation and alienation

Women felt alone and isolated both within the healthcare system and socially. For women with very rare conditions *"it is isolating and I've struggled quite a lot psychologically with it …I've never met anyone who has my condition or spoken to them."* (W13). When they were referred to general cardiovascular disease resources *"it just felt alienating because it didn't relate to me at all."* (W15). Many women longed for connection.

> *I felt very alone in those early years, and my God it would have helped me just knowing that there were other people. My cardiologist had told me at the time, about a week after my episode he had someone that had the same… I remember thinking, God it would be good to talk to her.* (W6).

Women with pre-existing disease or who were diagnosed during pregnancy could not attend antenatal or parenting classes as they were categorised as being high-risk.

> *I'd love to have sat in on the parenting class … and I didn't get to have a baby shower 'cause I was in hospital. So, these little things … you don't realise the social impact.* (W2).

Women from across all diagnoses either could not attend mothers' groups, or if they did the experience was uncomfortable, limiting the establishment of valuable peer mother networks.

> *They were all really freaked out … it was a very weird, isolating thing to go through.* (W12).

Making new connections

Support groups were only available for some of the cardiac conditions women were living with; for some conditions, there were no face-to-face or online support groups, for others there were groups for the general condition but not as it relates to younger people or women (e.g. cardiomyopathy). There were only international online groups for some of the cardiac conditions and some of the participants joined groups related to implantable defibrillators rather than the diagnosis that required the defibrillator. There were no support groups for women who had CDPP.

The women who read social media pages from the sideline may not have had the same level of engagement or benefited from the same level of support as those who did engage, instead having a vicarious support experience which they nonetheless described as helpful. Supports groups offered a space to connect, receive support and learn more about their diagnosis, including the psychological aspects of their condition and the day-to-day reality of living with a chronic illness. One woman had not met or communicated with anyone with the same diagnosis until she read a story about SCAD in a magazine and subsequently joined the online support group; this was 8 years after her PSCAD.

Women learnt more about their condition and management options in the groups, and so were better able to discuss their concerns and ask questions of their cardiologists. One woman found *“connecting with people who have been in [her] situation”* prior to having cardiac surgery was *“incredibly valuable in putting [her] mind at ease.”* (W3).

Online groups enabled varying degrees of engagement and meant women could connect at any time, without having to arrange childcare or transport; this was particularly helpful for women experiencing anxiety in the middle of the night.

> *I think without those support groups I really would have worried about my mental health. They have absolutely saved me. To be able to … write to people in the middle of the night and say “I’m feeling really scared. I can’t sleep. I’m gasping for air” – obviously I was having anxiety episodes, and people were saying “It’s okay. You’ll be okay. This is the same experience I had. This is what it’s all about.”* (W12).

Some women found accessing the groups early to be helpful, whereas others said that would have been too distressing with a risk of vicarious trauma.

> *… the first year is really hard, and you might be frightened to death that every night you go to sleep you’re going to die, but we’re all here and we didn’t and it’ll get better. So it gives some hope.* (W15).

> *I am kind of glad I didn't find them early on because you do see some horror stories, and … that there is someone ten years on still experiencing heart attack pain. You don't want to know that when you're just out of hospital for the first time.* (W16).

A downside of support groups is comparing yourself to others in an unhelpful way, *"You risk comparing your treatments and that might not be appropriate because we're all different"* (W20) and this might *"add a bit of fuel to the fire."* (W19). This was particularly relevant for international groups where women were receiving different advice and treatment, including being supported to have further pregnancies when Australian women were not, and this led to some women leaving those groups as it was too upsetting. Reading about other women's experiences gave the women strength and was *"quite humbling".* (W1). It was also *"so depressing…everybody had such a hard time it was hard to digest"* (W15).

While the groups provided a community and a space to share experiences, a weight of responsibility fell on the volunteer moderators, including logging on late in the evening to make sure women were not left feeling distressed and abandoned.

> *I have thought about the fact that someone might be sitting in bed in a hospital [in the middle of the night], feeling very isolated, and waiting for me to answer and join them to the page, so they could sit there and read.* (W15).

Not all women joined groups because they were not on social media, don't like group formats, because they did identify with the others in the group or their circumstances, or because they felt it was more helpful for them to find support elsewhere. For some, the issue was about not over-identifying or not wanting *"… to get caught up in that space…it's already in my head enough, I don't need it in my head any more than that"* (W17) or because *"…not focusing on it 24 hours a day is functional. It helps you get through sometimes."* (W2).

6.6 Discussion

This study is an in-depth exploration of the lived experiences of Australian women with CDPP. Drawing directly on women's stories, the analysis demonstrates that women with CDPP often have complex and distressing experiences that affect their sense of identity and mental health beyond their pregnancy or first year postpartum. Many of the experiences described by the participants are similar to those described in the literature on the lived experiences, mental health, self-identity and recovery of other populations such as cardiac, maternal, rare disease, chronic illness, trauma, birth trauma, severe maternal mortality and women with high-risk pregnancies (Dekker et al., 2016; Elmir et al., 2010; Lian & Robson, 2017; Liang et al., 2014; Shockley, 2012). The women in our study were part of most, or all, of those populations making them uniquely exposed to multiple and compounded risks.

There was a narrative consistency across the interviews despite the women being diverse in age, cardiac diagnosis and cardiac health status, parity and timing of diagnosis. The thread prevailing over the temporal and clinical differences was one of psychological distress, biographical disruption, identity, isolation, a necessitated re-imagining of their lives, and the process of multi-layered healing. The women were resilient in their recoveries; however, it is important to not romanticise their post-traumatic growth as something other than difficult and demanded by circumstance.

Mental health

Our research is consistent with previous findings that women diagnosed with CDPP describe feeling terrified, devastated, having a sense of doom, and feeling a loss of trust in the health system after having symptoms dismissed or misinterpreted health care providers as psychiatric symptoms (including “new mum anxiety”) (de Wolff et al., 2018; Dekker et al., 2016). Many of the women in our study had been acutely unwell, some with life-threatening episodes, they had intense and or prolonged pain and significant decreases in functional capacity yet most described the mental health effects as having the greatest impact on them. Further, the lack of mental health and social support was reported to be at least as pronounced and harmful as the sparse amount of cardio-obstetric clinical research informing evidence-based practice.

CDPP is associated with significant mental illness. A recent study found 26 of 40 participants had a major mental health disorder diagnosed after experiencing peripartum cardiomyopathy (PPCM) (Pfeffer et al., 2020). Compared to postpartum women without PPCM, the prevalence of major depressive disorders was 4-fold, for post-traumatic stress disorder 14-fold, and for panic disorder 6-fold. Women of reproductive age with heart disease report feeling stress, having challenges in taking control and making decisions, experiencing a lack of autonomy, and the importance of social support is identified (Dawson et al., 2018); these characteristics are also determinants of perinatal anxiety (Akiki et al., 2016). Women with pregnancy-related spontaneous coronary artery dissection (PSCAD) are reported to have almost twice as high scores for anxiety and depression than men and non-pregnant women who had SCAD (Liang et al., 2014). Further, a recent systematic review estimated the overall prevalence of perinatal depression to be 11.9% (Woody et al., 2017). Mental health conditions, heart disease, and pregnancy and postpartum are closely interrelated.

Our findings on mental health and cardiac disease are disappointingly predictable and are evidence of a persistent lack of integrated mental health and social support for women with CDPP despite evidence of its need (Liang et al., 2014; Woody et al., 2017). In particular, younger women appear to be more exposed to the risk of reduced mental health (Liang et al., 2014) and some cardiac conditions, including those experienced by this population, have higher rates of associated mental health issues (Johnson et al., 2020; Liang et al., 2014). The bi-directionality of mental health and cardiac disease means anxiety, depression and PTSD, as well as other mental health conditions, are associated with lower attendance at medical follow-up visits, poorer cardiac outcomes, more recurrent cardiac events and higher mortality (O'Neil et al., 2021; Rosman et al., 2019; Smaardijk et al., 2019).

Cardiac disease and suicide are leading causes of maternal mortality in middle- and high-income countries (Australian Institute of Health and Welfare, 2020b; Knight et al., 2019; Lommerse et al., 2019) though figures are likely to underestimate prevalence due to reporting differences and some data only including up to 42 days postpartum (Knight et al., 2019; Lommerse et al., 2019). A 15-year population study in Canada (Grigoriadis et al., 2017) is consistent with an earlier Australian study (Thornton, Schmied, et al., 2013) in identifying a peak in suicide occurring between 9 and 12 months postpartum. Critically, compared to matched living women, perinatal women who died by suicide had a similar pattern of use of non-mental health primary care and obstetric care to women who do not suicide before the index date, reflecting a missed opportunity to intervene (Grigoriadis et al., 2017).

Risks factors for maternal suicide include a history of mental illness, indigeneity, lack of recognition of mental health, medical illness, poor inter-disciplinary communication and lack of continuity of care (Australian Institute of Health and Welfare, 2020b; PMMRC, 2017). The prevalence of self-harm, suicidality and anxiety are increasing in young women (Stefanac et al., 2019) and when they seek support for self-harm and suicidal ideation young women report feeling patronised and dismissed, and that emergency department (ED) experiences increase their risk of future self-harm (Byrne et al., 2021). Thus, some of the risks for maternal suicide are increasing without a concurrent increase in effective intervention prior to pregnancy or once a woman is pregnant or postpartum. Further, the experiences of young women being dismissed, the lack of recognition and lack of continuity of care mirror the experiences of the women in our study when needing mental health, cardiac and obstetric care, indicating a repeated pattern and compounding and growing risk for poor mental health outcomes.

Autonomy and loss

In addition to the risk of delayed cardiac and mental health diagnoses, being dismissed and not receiving information when it was available reduced women’s agency and amplified the sense of low internal locus of control. Our findings were comparable to earlier research which reported that when women with maternal morbidity were dismissed and not listened to, or when they didn’t fully understand the situation, they felt disempowered and a lack of health locus of control that persisted months after their experience (Meaney et al., 2016; Redshaw & Hockley, 2010). Consistent with previous studies, for women in our study feeling confident in their sense of self was most challenged when they were in acute medical situations and when they experienced medical gas lighting; the dismissal and invalidation of their sense of self and lived experience (Byrne et al., 2017; Peeler et al., 2018). The clinical risks of not being believed were compounded by the emotional distress these experiences resulted in.

Women may experience difficulty in making decisions and in having others making decisions for them (de Wolff et al., 2018; Hess & Weinland, 2012; Hess et al., 2010). Most women in our study were advised to cease breastfeeding and or to have no further pregnancies. Consistent with earlier research, women in our study described having no bodily autonomy and that this advice was most commonly issued as a directive, and not introduced as a discussion with the opportunity to discuss their desires and values (de Wolff et al., 2018; Dekker et al., 2016).

This loss of autonomy as well as previous subfertility and pregnancy loss, and the abrupt change to expected family size is disempowering and complicates grief. Perinatal loss, infertility and medical reasons to not have children are ambiguous losses, which are characterised by the simultaneous physical absence of, but psychological presence of the foetus or infant (Boss, 2007; Boss & Couden, 2002; Lang et al., 2011). Ambiguous loss, for the children hoped for but never conceived, is associated with feeling frozen in grief, lack of support, and lack of recognition and rituals of grief. In the context of surviving a *"concurring crisis"* (Doka, 1999) of a complicated pregnancy or postpartum cardiac event this ambiguous and invisible loss may not be recognised by others including healthcare professionals and women may feel unable to talk about it (Boss, 1999). The mental health impact of ambiguous loss may thus be complicated by disenfranchised grief in which a person experiences a significant loss and the resultant grief *"is not openly acknowledged, socially validated, or publicly mourned"* (Doka, 2008 p224) which exacerbates their suffering.

Being physically unwell with cardiac disease affects women's ability to care for their newborn or return to the normal activities of daily life and these limitations contribute additional distress (de Wolff et al., 2018; Dekker et al., 2016). Further, traumatic birth (as experienced by some of our participants) impacts a woman's experience of motherhood and her initial relationship with her baby, with women reporting lost bonding time, feelings of failure and the emotional impact of 'relinquishing care of the infant' (de Wolff et al., 2018; Elmir et al., 2010). Women struggle to surrender care even when acutely unwell, and the importance of their role as mother is not always fully appreciated or facilitated by health professionals (Power et al., 2015). Hinton, Locock, and Knight (Hinton et al., 2015a) highlight the difficulties of being a new mother in critical care, including the anguish of women who were separated from their baby, how important breastfeeding was for them, as well as the need for more support.

Identity

Physical and mental illness, loss, and embarking on motherhood, especially for the first-time, provoke a changing a sense of self and of self-identity (Asbring, 2001; Charmaz, 1983; Doka, 2019; Wisdom et al., 2008). Motherhood is a fracturing of a woman's identity to allow space for a new identity in her new life (Laney et al., 2015). This rupturing and reformation is a multidimensional process comprising the stages of triggering event (becoming a mother), loss of self, and redefining the new self; the women in our study repeated this process with the trigger event of CDPP. The women's descriptions of cardiac and mental illness, pregnancy, birth and motherhood, identity and recovery in our study were congruous with Wisdom's analysis relating to mental illness (Wisdom et al., 2008). In this, participants described a loss of identity/self, the duality of being ill and well (of having cardiac disease and being a mother), perceptions of normality (the 'new norm'), and their specific concerns about the impact on parenting, and recovery and reconciliation.

Pregnancy, birth, the postpartum period, breastfeeding and illness are fundamentally embodied experiences. The body is our access to perceiving and interacting with the world and is integral to identity and sense of self (Merleau-Ponty & Landes, 2012). Biographical disruption is a disruption or disturbance of one's embodied perception and experience of the world (Bury, 1982). A body changed by pregnancy and motherhood, and which is also now an unreliable body due to cardiac disease, complicates and unsettles existing identity and sense of self, and changes the way one interacts with the world. Illness (cardiac, mental, maternal) disrupts that which was taken for granted such as being able to pick up your baby, work, or play in your team sport, and causes a *"fundamental re-thinking of a person's biography and self-concept"* (Bury, 1982 p169). Moreover, chronic illness involves a continued adaptation, an ongoing struggle to "maintain control over the defining images of self and over one's life" (Charmaz, 1991 p5). As their cardiac status, mental health and experiences of mothering change, women with CDPP have an enduring experience of re-defining self and identity, managing their illnesses and grief, and accepting and making sense of their lived experiences.

Self-identity is formed through reflection of our peers, and verified or rejected through our interactions with others, including healthcare professionals, through whom we internalise a felt sense of what it means to be ourselves, incorporating values and judgments that have been perceived (Doka, 2019; Stets & Serpe, 2013). Mothers build their identity in part through engaging with peers in antenatal and mother's groups that many of our participants were unable to join. People with illness compare themselves to others they know with the condition, or the knowledge they already had of the condition. Women change their self-perception post cardiac event, both positively and in the sense of losing one's prior self (Shockley, 2012). Most women in our study had no, or few, peers of other mothers with similar conditions with whom to compare and mirror. Redefining self-identity was both complex and integral to healing for the women in our study who had multiple triggers for biographical disruption and loss of self. Having cardiac disease amplifies the physical, emotional and sociological vulnerability that women experience perinatally and in the postpartum period (Dekker et al., 2016).

The role of stories

The women in our study largely traversed these experiences and phases without connection with peers and this sense of isolation increased their suffering. When they were able to connect and 'see themselves in the stories of others', often through Facebook support groups, they mostly felt validated and re-assured that others had similar symptoms and experiences, and that they were simply still alive. Stories are not inherently positive or even benign, and can exclude as much as they include, as a couple of women in our study experienced when they did not identify with others in the online groups. The key determinant of the nature of a story is who is allowed to narrate it, who is the protagonist, so even in not identifying with other women, that process helped define their own identities. That is, the telling of their stories is more than a retelling of events, rather it can be reparative and facilitate the conception of their new self (Kostick et al., 2019). The women in our study found several ways to control or at least own their own narrative. They did this by not staying 'immersed in their illness', seeking improved communication, providing others support, advocacy, and involvement in research (Green, 2004). As they redefined and clarified their self-identity they shifted from being a 'cardiac patient' or an 'obstetric patient' to being a woman and mother who juggles having a cardiac condition along with all the other roles and tasks that she needs to do each day.

Recovery

Regaining a sense of control and autonomy was an important step in recovery and this was underpinned by their sense of self. Recovery is not taken as returning to one's premorbid condition or to cure, rather it is about recalibrating and finding equilibrium; having a chronic illness means having to adjust and re-adjust, developing new ways to manage for life (Charmaz, 1991).

Recovery for the women was multi-factorial and non-linear. It was comprised of a partial return to their previous health and life and a partial creation of a new identity and life, now with a chronic health condition and a baby. Our study is consistent with previous research that found that women struggle to recover psychologically, that little or no professional mental health support was provided and that women felt invisible and isolated during recovery (de Wolff et al., 2018). Of note, Koutrolou-Sotiropoulou, Lima, and Stergiopoulos found that more than half of women with PPCM did not return to premorbid levels of emotional health after 1 year despite 68% having recovered cardiac function, highlighting the persistent emotional toll of CDPP on young mothers (Koutrolou-Sotiropoulou et al., 2016).

6.7 Limitations and strengths

A strength of this study is that it is the first study exploring women's lived experiences across a spectrum of CDPP, enabling the inclusion of women with rare diseases who otherwise may not be included in research due to small numbers. The interviews facilitated women in being able to be authentic and share what was of most importance to them. The themes developed provide rich and detailed analysis of women's experiences. This knowledge contributes valuable information to a small body of knowledge on women's experiences and values relating to CDPP.

The majority of women with CDPP interviewed in our study had not debriefed their experiences, or told their story, even to themselves. The opportunity to narrate unscripted was enlightening for many of them as they reflected upon their own distress and recovery, and clarified their goals for themselves and future girls and women. In this way, having a voice and telling their story was part of their self-mastery and enabled them to (re-)construct their life story retrospectively, in the moment, and prospectively (Kerr et al., 2020). Writing your own story also allows for the possibility of turning negative experiences into positive ones.

Methodological limitations include that the narratives may be subject to recall bias, both positive and negative, as time has passed since the experiences discussed. Further, the generalisability of our findings is limited to English-speaking patients with no representation of Australian First Nations women or minority ethnicities; no interviewees were in same-sex relationships and there was no inclusion of women living with disability. The majority of interviewees responded to social media recruitment strategies and thus women not using social media are unlikely to be included in this study. Whilst including a range of cardiac diseases is a strength, it is also a limitation, in particular when consideration is to be given to responding the needs identified. More studies are needed to understand specific needs of women with CDPP, including the needs of diverse populations and changing needs over time.

6.8 Conclusion

Acknowledging and understanding the breadth, complexity and depth of women's experiences of CDPP is a fundamental step in improving outcomes. These findings provide a unique insight into women's experiences and challenges across a spectrum of diseases and timing of disease. Most women in this study did not report isolated or singular trauma or distressing event, rather there was a layering of traumatic experiences, and the number, nature and recovery from previous traumas informed and complicated the trauma associated with their cardiac disease in pregnancy and the postpartum period. The physical, quality of life and mental health impacts of CDPP are long-term and enhanced continuity of care beyond the routine 6-week postpartum check is essential.

It is recommended that mental health screening timeframes reflect the research findings of both antenatal and late postpartum mental health prevalence and include prior history. Early assessment and treatment increase the chance of improved short- and long-term mental health and cardiac outcomes. In addition, it is essential that mental health screening for women with CDPP is broader than routine perinatal depression screening, includes anxiety, depression, PTSD and other mental health disorders, and is integrated in care pathways. Further research is required to understand long-term outcomes and to refine the findings for specific disease cohorts to be able to provide services and support that meet the needs and values of women with cardiac disease in pregnancy and the first year postpartum.

6.9 Chapter summary

Chapter 6 has provided deep insights into the mental health and isolation experienced by women with CDPP. The lack of recognition of their distress and their needs is a characteristic of the lack of person-centred care described in Chapter 4 and lack of voice and challenges self-advocating described in Chapter 5. The following chapter describes the experiences mothering as a woman with CDPP, and highlights the array of challenges and loss that women face.

Chapter 7: When worlds collide: mothering with cardiac disease in pregnancy and postpartum

7.1 Publication

The results for this chapter have been submitted for publication with *BMC Pregnancy and Childbirth*.

7.2 Chapter introduction

This chapter is a qualitative examination of women's experiences mothing, answering the thesis research Question 3 *"What is the impact of having cardiac disease in pregnancy and the first twelve months postpartum (CDPP) on women's experience of mothering?"* Chapters 4 and 5 explored women's healthcare experiences including the important issues of lack of voice and a sense of disempowerment, and the negative impact these had on women's mental health. Chapter 6 provided an in-depth analysis of women's mental health associated with CDPP which identified that women can have complex psychological responses to their illness, influenced by their healthcare experiences, pregnancy and childbirth, individual traits and past histories. Women felt very isolated, and their poor mental health persisted for many years, which may affect their experiences of mothering.

7.3 Background

The transition to motherhood is a major developmental stage that requires physical, emotional, and social adjustment and it is associated with a significant reconstruction of self (Rogan et al., 1997). Mothering is a woman's emotional and/or physical care for a dependent child (Vallido et al., 2010). Further, mothering "*involves a number of mental health costs, including time, physical and emotional energy, conflicts with other social roles, and the economic burden of childrearing* (Balaji et al., 2007 p1388). Mothering while recovering from a serious cardiac event or deterioration of an existing cardiac condition adds complexity and potentially introduces barriers to fulfilling mothering goals, and motherhood as a primary identity is endangered by illness (Vallido et al., 2010).

Studies of mothers with serious maternal morbidity or maternal near-miss events who require an initial separation from their newborn, describe women experiencing distress, delayed or impaired infant bonding, and challenges establishing breastfeeding, all of which require additional support (Hinton et al., 2015a, 2015b; McCoyd et al., 2018).

Cardiac disease is a leading cause of maternal morbidity and mortality (Knight et al., 2019; Regitz-Zagrosek et al., 2018). In this research we define CDPP as pre-existing or newly diagnosed cardiac disease in pregnancy or in the first 12 months postpartum, including acquired, congenital and genetic conditions (excluding hypertension and preeclampsia).

While these conditions are pregnancy- and postpartum-related, and partial or full recovery may be achieved, women who experience CDPP now have chronic cardiac conditions and need to continue to adjust and adapt over time.

A meta-analysis of women of reproductive age with heart disease found that women felt stressed, experienced a lack of autonomy, have difficulty in taking control and making decisions, need enhanced social support (Dawson et al., 2018). The limited available research on women's experiences of CDPP describes women facing challenges managing their own acute and chronic cardiac condition whilst simultaneously mothering their infant and young children (de Wolff et al., 2018; Power et al., 2015; White et al., 2009).

Postpartum women have an increased vulnerability to mood disorders, including an overall estimated prevalence of clinical depression of 17% (Shorey et al., 2018), anxiety 20.7% and PTSD 1.1% (Fairbrother et al., 2017). Further, a substantial number (15-30%) of women report subclinical depressive symptoms postpartum (Goodman, 2004). Women with CDPP have an even greater risk of being diagnosed with a major mental health disorder, including 4-fold risk of major depressive disorder, 14-fold for posttraumatic stress disorder and 6-fold for panic disorder (Liang et al., 2014; Pfeffer et al., 2020). Women's experiences of poor mental health are likely to affect their experiences of mothering with CDPP.

The aim of this study is to explore the experiences of mothering from women who have had cardiac disease in pregnancy and postpartum.

7.4 Methods

7.4.1 Study design

We conducted a qualitative study to explore women's experiences, validate their stories and increase awareness of mothering with CDPP, which is particularly relevant in under-researched areas such as this (Denzin & Lincoln, 2011). The study concept was discussed with clinical and community groups from the NSW Heart Foundation. Ethics approval was granted by the University of Technology Sydney's *Human Research Ethics Committee (ETH19-3372)*.

7.4.2 Participants and recruitment

Criterion-based purposive sampling (Palys, 2008) was used to engage women who had a diagnosis of CDPP and were willing to participate in an in-depth interview. Participants were mothers living in Australia who have been diagnosed with cardiac disease (excluding hypertension and preeclampsia) any time prior to pregnancy through to 12 months postpartum. Recruitment was via Facebook pages and groups of consenting cardiac groups and organisations, as well as via invitations distributed by cardiac support groups to members' emails and or group newsletters. Recruitment continued until we had adequate depth and breadth of data to sufficiently describe and analyse the participants' experiences and answer our research question (Braun & Clarke, 2021b).

Twenty-five women with acquired (n=12), congenital (n=5), and genetic (n=9) CDPP participated in the interviews (one women had both congenital and genetic conditions). The women were diagnosed before pregnancy (n=9), during pregnancy (n=6) and postpartum (n=10). The majority were first time mothers (n=15), 5 had their cardiac diagnosis associated with the 2nd pregnancy, 4 with their 3rd pregnancy and 1 with her fourth pregnancy. Age at time of interview ranged from 28 years to 59 years (median age 39 years). Participant diagnoses are provided in Appendix 1.

7.4.3 Data collection

We used semi-structured interviews, an established qualitative approach when exploring under-researched topics. This technique enables responsiveness and reciprocity between the interviewer and participant, provides space for a diversity of perceptions, and allows participants to focus on the issues that are most important to them (Kallio et al., 2016). An interview guide was developed and data were collected via individual interviews conducted by phone. Interviews were conducted by a single interviewer (JH) and were between 24 and 90 minutes in length. The interviews were audio-recorded with permission, or hand-transcribed verbatim, including notable non-verbal responses such as crying or laughing. Data were kept confidential.

7.4.4 Data analysis

Inductive reflexive thematic analysis was used as it is flexible and accommodating when unexplored phenomena are described, enables identification of similarities and differences across the data set and allows for nuanced theme development (Braun & Clarke, 2022; Byrne, 2022). Informed by the six stages of analysis outlined by Braun and Clarke, data coding and theme generation was iterative and responsive to developing patterns (Braun & Clarke, 2006). All study team members listened to the interviews and read the transcripts. JH led the analysis by immersing herself in the data, generating and refining codes and themes, and selecting illustrative quotations.

Quality was established using the guidelines described by Braun and Clarke (Braun & Clarke, 2021a). In particular, the researchers engaged in ongoing discussion, reflection and development of the codes and themes, exploring individual and shared perspectives on the patterns within and across the women’s stories.

7.5 Results

Analysis of the data generated four themes: 1) A mother first, 2) It’s a big deal to me, 3) Not the motherhood I imagined, and 4) Interrupted connections.

7.5.1 Theme 1: A mother first

In self-identity, physical recovery and world-view, the women interviewed presented as mothers first, or mothers still, regardless of their cardiac condition.

I need a hand here

Women felt at times overwhelmed and unsupported, especially in the early days of being a mother, with no-one asking "*Is there anything you need*?" (W2). One woman with heart failure was left unaided to give her newborn his first bath in neonatal intensive care.

> *"Oh, can someone help me?" I'm like … no, never bathed a baby before, let alone a 34-week-old baby.* (W2)

Advice provided and discharge planning did not always account for the women's needs or the centrality of children in their lives; this left women feeling unsupported and concerned.

> *I still had a 19-month-old at home, with a newborn, that was a bit – a little bit stressful, especially – because I remember one day at home my arm started hurting again [like when she had a heart attack].* (W10)

One woman sought information about the safety of her newly prescribed cardiac medication while breastfeeding and was advised as follows.

> *"You can just monitor him to see whether he turns blue at home. If he does, stop doing it."* (W12)

The gamble of self-sacrifice

Despite feeling unwell before and after diagnosis, women prioritised their role as a mother and the needs of their children, even if this negatively affected their cardiac health.

> *I felt so very unwell, but anyway I just kept going. I had four children, two little twins, I had to keep going.* (W18)

Being a mother-first and putting themselves last influenced their responses to cardiac symptoms and decisions about seeking care. From negotiating with ambulance staff to go to hospital only *"if we can get me down there, get me checked, get back"* (W7) in quick time as they had 'things to do', to not calling an ambulance at all. The women's internal dialogues calculated children's sleep time, school pick-up schedules, and partner's needs against her evolving cardiac event.

> *And, having two young kids, I thought maybe I'll just drive myself up to the hospital, you know, and get it checked out. But I didn't want to drive if it was going to be really serious, but I also just didn't think it was quite serious enough to wake my husband and get him to wake the kids and be sitting in an emergency room. So, I woke my husband and said I think I might just call an ambulance just to be safe, you stay here with the kids, it's probably nothing*. (W9)

What about my children?

Women were confronted with decisions about whether to undertake prenatal genetic diagnosis (if applicable and available) or test their children for the cardiac condition they had. This added complexity to their recovery, future fertility plans, and emotional distress that was not necessarily recognised or responded to. Not all women had access to genetic counselling or support through this process.

> *You know, there was just no understanding for the pressure that I was feeling being a new mum in a situation worrying about my child dying. I was genuinely concerned he was going to die. I was concerned I was going to die*. (W12)

Some women (and their partners) were anxious to find out their children's results to ensure they were safe.

> *But for me, the anxiety that I felt around thinking that my son had it was so overwhelming, that I knew that if I was ever going to have another baby, that there was just no way I would ever do it if the child would have the condition. For me personally, it's just a very scary thing. The child would need to be on medication their whole life. They wouldn't be able to play sport. Very restrictive life really.* (W12)

Other women chose not to test their children, *"I've lived my whole life with it, it hasn't really affected my life too much and I was diagnosed at 11"*. (W21) A key reason for not testing, and not telling their children until they were adults, was not wanting to restrict their children's lives.

> *I would rather not wrap her up in cotton wool. So, I'm sort of thinking … when she turns 18, I'll tell her she should probably go and get tested for herself, but until then, I'm just going to let her be a normal child.* (W3)

The women also had to evaluate how much information to provide their children about the seriousness of their own health status and how to manage this delicate discussion.

> *Obviously, I had to contemplate that I might die, it was quite a real possibility and I had young children and I remember talking to the social worker and how was I going to tell my kids, because that's a really hard conversation, and like I do have a strong faith so that made it kind of easy to have a way forward to tell that, but at the same time I didn't want to traumatise them and tell them too much or not enough.* (W20)

Regardless of whether they tested their children or not, the women felt the weight of possibly passing on their heritable condition.

> *I think that the main thing is the guilt that you carry, that you can give it to your children. … and at times it does still get me, the guilt of, "Oh, God, will it affect their lives?" I can't say, but I would hope that it won't, it won't cause them any depression or cause them any upset or heartache in their lives.* (W21)

7.5.2 Theme 2: It's a big deal to me

In acute situations, timely treatment of the cardiac condition is paramount. While this was critical for women, being very unwell did not reduce women's desire to breastfeed or have more children. On the contrary, their current experiences of CDPP put their fertility and breastfeeding experiences in the foreground.

Lost fertility choices

Women were commonly advised to avoid future pregnancies. Even though they recognised the risks involved and largely accepted the advice, women still found this distressing, *"I was horrified, because I was wanting more"*. (W16)

Decisions to not have more children were multifaceted and individual. This included considering the perspective of their partners, and foregoing the desire for another child in order to still be alive for their first child, mixing the optimism of new life with the anxiety of foreshortened life.

> *When my heart became so unstable, it was actually right about the time that we were planning to try for another baby. I guess it just became obvious that really, I wasn't up to it physically. We made the decision that it was better for our son to have a mother than to get into the situation where my health was really put on the line for the sake of having a sibling*. (W13)

Several women had conceived using assisted fertility treatments, some undergoing many IVF cycles and miscarriages, and they now faced not being able to proceed with the planned embryo transfers that they had fought so hard for.

> *You look at your kids and you think you've got a frozen embryo sitting there in [the IVF clinic], it's a hard one to sort of throw in the trash. So that's a hard one.* (W15)

Further suffering occurred for two women who had unplanned pregnancies and whose cardiac, obstetric and maternal foetal medicine specialists advised *"that we terminate and not carry on with the pregnancy, which is what we ended up doing, and I mean I was desperate to keep it."* (*W*23) Fear of pregnancy and associated cardiac health issues also affected the women's intimate relationships.

> *I think as far as an illness goes, and that experience [unplanned pregnancy], it really impacts on your intimate relationships, because … it's not worth the risk. The emotional risk (and risk of pregnancy), so I think that long term has had an impact. As much as we love each other I still just go, "Yeah, yeah, sex is not high on the list."* (W2)

Breastfeeding

Women's experiences of breastfeeding were challenging due to previous cardiac surgery causing chest numbness and sensitivity, affected mammary tissue, implantable cardioversion devices, painful arterial lines, dehydration, inability to sit upright without fainting, difficult births, separation from their babies and commencement of medications contraindicated in breastfeeding. Some women benefited from lactation consultant support and re-assurances from health care professionals, while others felt enormous pressure with little accompanying support or were advised to ‘just use formula’. Despite the challenges, being able to breastfeed was “a big deal” for women.

> *Breastfeeding was terribly tricky. I put that down to [my daughter’s] traumatic birth and the fact that she didn’t have skin to skin contact for so long*. (W21)

The advice to stop breastfeeding was difficult to accept, especially when it was not informed by strong evidence.

> *Well, they were just giving their medical advice and I was just listening … but inside I was just going, I'm not [stopping breastfeeding]. So, I just let them talk and say what they said and I just listened. I think I said "Well, if you don't know, then how can you give advice?" You know, it could be or it couldn’t be. This is a really important thing for me. It's not just something that I'll stop lightly and it doesn't mean anything.* (W18)

Many participants felt there was little acknowledgement of the physical and emotional aspects of the immediate and undesired cessation of feeding.

> *I found it really, really hard because I knew that my youngest was more than likely going to be my last. I guess it was the one space that she and I had, in a really busy house, that was ours. So, yeah, I found that really hard*. (W17)

7.5.3 Theme 3: Not the motherhood I imagined

Restrictions

Physical restrictions and limitations affected almost all aspects of daily life and mothering, and the women received no assistance such as occupational therapist input.

> *I wasn’t allowed to walk up hills, I wasn’t allowed to walk for periods longer than five minutes. I wasn’t allowed to lift my kids, and I had two kids. And I live on a hill. I couldn’t push the pram; I couldn’t do anything. So the whole time, I’m going, “How am I going to be a mother when I can’t do this stuff?”* (W7)

Activities of daily life that were previously undertaken without a thought became stressful events that required planning and support.

> *I guess it's a hit to your confidence. So there have been lots of little milestones to me that I'd never have thought were milestones, like taking my son and my youngest child to a shopping centre by myself. I would never have thought twice about that, but that was a really big thing to do. Or staying at home overnight with the two girls by myself.* (W17)

Most women were instructed not to lift anything heavy, including their babies and children, causing significant distress.

> *For me, what kills me is not being able to just lift her, because she likes to be picked up and bobbed around when you're standing up, and that kills me that I can't do that …I just kind of worry about the future bonding there, when she realises that I can't do it, you know*. (W25)

Being unable to lift their children also upset their older children, adding to women's distress.

> *My three-year-old hates it. Even now she still hates it and will ask when I'm going to be strong again. Not in a big way, but just in little things. Like when I take her to kinder and pick her up, other parents will sometimes carry kinder kids out and I can't do that*. (W17)

Relinquishing care

As a consequence of their ill-health, hospitalisation and ongoing physical restrictions, women strongly appreciated help from other to care for their children but also grieved not being able to do it themselves.

> *It felt like everyone around me was making decisions for me on how to care for my kids because they were worried about me. But I felt excluded from parenting my own kids.* (W7)

7.5.4 Theme 4: Interrupted connection

For many women a consequence of having CDPP in pregnancy was a complicated vaginal birth, caesarean birth, general anaesthetic and an initial postpartum recovery spent in intensive or cardiac care, separated from their newborn. In addition, several women's newborns required extra care, including resuscitation. This separation at birth was frequently distressing; *"I remember waking up screaming, "Where's my baby?" Because I had no idea what had happened … the whole thing was actually quite distressing." (W3)* Another woman was transferred to another hospital immediately postpartum: *"I was in tears, going, "Get me back over to the [other hospital] … I just want to go to my baby." (W1)*

> *I felt that the time that I had away from him when he was first born, it was horrific for me. I didn't get to have those cuddles or those first nights even. I can't even remember the amount of time. It felt like months and months that I was apart from him*. (W16)

Most women who had CDPP diagnosed postpartum were also separated from their infant which caused distress in addition to specific concerns about breastfeeding, *"I went for days without seeing my newborn. ... it was really, really hard." (W7)*

The interrupted mother-infant connection was not only due to physical separation when they were in hospital, it was also due to the physical and emotional impact of their CDPP. Regardless of cause, women felt they had missed out on early and continuous connection and cherished time with their newborns and older children.

> *The first 3 months after the heart attack were a blur …. I feel like I've missed that part of my baby's life*. (W24)

> *I feel sad because my eldest son missed out so much time, and I missed out on time with my eldest son. I feel robbed because I couldn't do anything. I literally had to just sit on the couch for six months*. (W7)

For some women, the interruption in connection lasted for more than hours or days, and was associated with impaired bonding and postnatal depression.

> *I felt very detached at points. Probably up till about six weeks, really.* (W1)

> *It was probably a good nine months before any kind of bond, and I remember the first day that I actually felt it was [when] someone loaned [me] their kangaroo pouch* [baby carrier]. (W14)

7.6 Discussion

Our findings provide a unique insight into the array of unrecognised and unmet needs of mothers with CDPP and the gap between their healthcare expectations and their experiences of mothering with CDPP. The overarching theme is the primacy of motherhood and mothering in the women's view of themselves, their needs and their priorities. This contrasts starkly with the invisibility in the literature and clinical care of these important issues for women, including their children, having future pregnancies, and breastfeeding. In addition, healthcare professionals are not always cognisant of the propensity of mothers to foreground the needs of their children and at times, their partners, and to under-estimate and downplay their own health needs, increasing the risk of cardiac morbidity and mortality. Issues surrounding fertility and breastfeeding, and possible genetic and cardiac testing of their children were paramount to women, and they struggled with the lack of acknowledgement and care during discussions of these matters. Being separated from infants and older children was distressing and relinquishing care was emotionally complex. Navigating physical restrictions impacted women's ability to mother, and live in the manner they imagined they would.

Mothering as an identity, and the expectations of oneself as a mother have been explored in the literature and is an evolving field (Balaji et al., 2007; Lawler et al., 2015; Luthar & Ciciolla, 2015; Power et al., 2015). Fewer studies have examined motherhood with an acute illness, severe maternal morbidity or near-miss, or chronic illness (Dorgan et al., 2013; Hansen et al., 2022; Power et al., 2011). However, with the increasing prevalence of CDPP (Regitz-Zagrosek et al., 2018), this work is essential to improve women's maternal outcomes, address rising health costs (Admon et al., 2018), and promote optimal outcomes for infants with unwell mothers (Hinton et al., 2014; Hinton et al., 2015b). Women may be influenced by the ideals of motherhood and expectations of mothers in the societies they live in. For example, the Western notion of the "perfect mother" is selfless, protective of her children and focused on her child's wellbeing (Barlow & Chapin, 2010). A recent Indonesian study of the experiences of women diagnosed with cardiac disease also described high expectations of the "good mother", including infants being removed from the mother by family if she was unable to meet the expected level of parenting (Sutantri et al., 2020). Women in our study expressed grief and frustration about not being able to mother in the way they expected. Women also expressed anxiety and guilt about possibly or actually passing cardiac conditions to their children, thus failing this ideal of the perfect mother (Francis-Connolly, 2000).

Bury's (Bury, 1982) concept of the biographical disruption examines the effect of illness on identity; Wilson (Wilson, 2007) proposes that this needs to be extended in view of mothering with an illness, and to instead examine the relationship between illness and identity. In view of mothering with CDPP, we suggest that a woman's identity as a mother is the subject (not the illness), and that mothering needs to be examined in light of managing a diagnosis and illness. This shift is consistent with women's foregrounding of their identity as mothers over their identity as someone with cardiac disease.

Most women in our research had been advised to avoid further pregnancies and this was difficult and distressing advice, with the manner it was communicated compounding the women's suffering. Our previous article (Hutchens et al., 2022) found women with CDPP experienced significant anxiety and depression that persisted many years after their CDPP, and it is possible that being advised to avoid pregnancy may contribute to women's poor mental health. This is congruent with research examining the impact of a cancer diagnosis and the future impacts on childbearing from the recommended treatment in which women felt distress and depressive symptoms, as late as ten years after their diagnosis (Canada & Schover, 2012; Gorman et al., 2010; Logan et al., 2019). The way that advice about future pregnancies is communicated is critical to person-centred care and women's mental health, and healthcare professionals could look to guidelines used in fertility clinics to model best practice (Dancet et al., 2011).

There has been a small amount of research focusing on issues of risks and decision-making for family planning (Cauldwell et al., 2017; Ngu et al., 2014a, 2014b), and some on contraceptive choices and use, and unplanned pregnancies for women with cardiac disease (Cauldwell et al., 2017; Holton et al., 2018; Kaemmerer et al., 2012). Women with cardiac disease have similar desires to have families as women without cardiac disease; they may underestimate risks and HCPs may underestimate women's desire for children and not provide adequate family planning education and counselling. Australian research found that women with chronic non-communicable diseases (NCD) were significantly more likely than women without an NCD to have ever been pregnant, have an unintended pregnancy and a have termination of pregnancy (Holton et al., 2018). An earlier review of termination of pregnancies performed for maternal indications in an Australian tertiary obstetric referral hospital found 12.5% of cases were due to a cardiac reason (Barrett et al., 2011). In all cases the cardiac diagnosis was known before conception and contraceptive rates in this at-risk group were poor, warranting attention.

Being advised to cease breastfeeding was an additional source of anguish for some women in our research, consistent with the literature (Dekker et al., 2016). Women can have mixed experiences and feelings about breastfeeding, but having choice is imperative and when this autonomy was removed it compounded the anguish and grief women experienced. Breastfeeding was more than nourishing their infant for the women in our study, it was about connection, which is consistent with the literature on women's descriptions of their breastfeeding experience being one of closeness with their infant (Burns et al., 2010).

Lastly, our study shows that women require additional support to care for their children when they are unwell or have physical restrictions (such as limits on lifting), and to adjust to their new identity as a mother with a chronic cardiac condition.

7.7 Limitations and strengths

Our article provides a unique insight into the multifaceted experiences of mothering with CDPP. This is the first study exploring women's experiences as mothers across a spectrum of CDPP, enabling the inclusion of women with rare diseases who otherwise may not be included in research due to the low prevalence of these conditions. The inclusion of only English-speaking women is a limitation of our study as findings may not relate to the experiences of racially-diverse women. In addition, many interviewees responded to social media recruitment strategies thus limiting involvement for women without social media access.

7.8 Conclusion

Our study provides a unique snapshot of women's experiences of mothering across a variety of cardiac diseases during pregnancy and the postpartum. While the findings include positive aspects, the majority of themes and experiences were negative, or mixed. Women felt unseen as mothers, and had constraints on activities of daily living and mental health concerns due to their cardiac condition. Their ability to mother, their children's health and the advice to cease breastfeeding and to avoid future pregnancies were central concerns for women. Their experiences were complex and the issues of having CDPP continued well beyond pregnancy and the first year postpartum.

It is recommended that further research be undertaken, including co-design of longitudinal studies, and for healthcare professionals to inquire about women's needs and refer to appropriate allied health and support services. Understanding women's experiences and needs as mothers with CDPP is an essential part of a collaborative approach to tailoring services to meet women's needs and improve outcomes.

7.9 Chapter summary

This chapter highlighted the marked affect that CDPP has on women's experiences mothering. Women felt unseen as mothers and had enduring physical constraints and reduced mental health. They felt compromised in their ability to mother how they desired, and had concerns about their children's health, advice to cease breastfeeding and to avoid future pregnancies. The following chapter builds on this data by exploring women's quality of life as mothers with CDPP using a quantitative survey instrument, the Mother-Generated Index.

Chapter 8: Quality of life for mothers with cardiac disease in pregnancy and postpartum: the Mother-Generated Index

8.1 Publication

The results for this chapter are being prepared for submission for publication.

8.2 Chapter introduction

This chapter is a quantitative assessment of the impact of cardiac disease in pregnancy and the first year postpartum (CDPP) on women's quality of life and experiences of mothering, and answers research Question 3 *"What is the impact of having CDPP on women's experience of mothering?"* and Question 4 *"What is the impact of having CDPP on women's quality of life?"* Chapter 6 described women's complex and often enduring poor mental health outcomes following CDPP and Chapter 7 provided a qualitative analysis of women's experiences mothering with CDPP, including the effects of their mental health. This chapter focuses on women's quality of life as mothers with CDPP using a quantitative survey instrument.

8.3 Background

Cardiac disease complicates an estimated 1-4% of all pregnancies and is a lead cause of maternal morbidity and mortality (Knight et al., 2019; Regitz-Zagrosek et al., 2018). Cardiac disease in pregnancy and postpartum (CDPP) is pre-existing or newly diagnosed cardiac disease in pregnancy or in the first 12 months postpartum. CDPP includes acquired, congenital and genetic conditions, incorporating a variety of structural heart and aortic diseases, cardiomyopathies, rhythm disorders, ischaemic heart disease, and arterial dissections. Data suggests there are increasing numbers of women with cardiac disease embarking on pregnancy, and rising numbers of women receive an initial diagnosis in pregnancy or the postpartum (McClure et al., 2011; Mehta et al., 2020; Regitz-Zagrosek et al., 2018). Whilst pregnancy and postpartum is for a delimited to twelve months postpartum, CDPP is associated with long-term cardiac outcomes.

There is limited research on women’s experiences and health-related quality of life (HRQoL) outcomes for CDPP. The available literature reports an enduring lower quality of life (QoL) (Koutrolou-Sotiropoulou et al., 2016; Rosman et al., 2019), and an increased risk for diagnosis with a major mental health disorder, including anxiety and depression (Liang et al., 2014; Pfeffer et al., 2020). Despite women wanting research to include topics such as HRQoL and issues relating to mothering, to date most literature has focused on clinical outcomes rather than patient-defined outcomes (Hall & D’Souza, 2020). Patient defined- and reported-outcomes are essential in understanding and improving clinical and broader QoL outcomes and are integral to person-centred care and shared decision-making (Rumsfeld et al., 2013).

Mothering is a multifaceted sociocultural phenomenon (Balaji et al., 2007; Lawler et al., 2015; Luthar & Ciciolla, 2015; Power et al., 2015). Some studies have examined reproductive choices and motherhood for women with an acute illness, severe maternal morbidity or near-miss, or chronic illness (de Wolff et al., 2018; Dorgan et al., 2013; McCoyd et al., 2018; Power et al., 2015; Vallido et al., 2010). However, with increasing prevalence of chronic illness and CDPP in particular (Lima et al., 2017), it is important to understand women’s experiences and QoL as mothers with CDPP to improve outcomes for mothers who are unwell or have physical limitations (Hinton et al., 2015b).

The aim of this article is to explore the impact of cardiac disease in pregnancy and the first year postpartum (CDPP) on women’s quality of life and experiences of mothering.

8.4 Methods

8.4.1 Study design

At present there are no validated patient-reported outcome measures (PROMs) specific to individual or combined cardiac diseases in pregnancy and postpartum, or for women’s experiences of mothering with cardiac disease. Therefore, data were collected using a modified Mother-Generated Index (MGI) questionnaire which was completed as part of an anonymous online survey using the Qualtrics Software (Nov 2021) and analysed using IBM

SPSS Statistics for Windows, Version 28.0. Ethics approval was granted by the University of Technology Sydney's *Human Research Ethics Committee (ETH21-5695).*

8.4.2 Participants and recruitment

Twenty-five participants were recruited from a study Facebook page, established Facebook cardiac support groups and cardiac organisations. Participation was voluntary and did not attract any financial benefit. A detailed description of the study was provided on the study website, Facebook page, shared posts and advertisements. Consent was explained and confirmed by commencing the survey. Data were collected from August to November 2021.

The inclusion criteria were mothers who have been diagnosed with cardiac disease prior to, during pregnancy or up to 12 months postpartum, living in Australia and who give birth to one or multiple babies at least 20 weeks' gestation or 400g birthweight. Women required sufficient English language skills to understand the study information and complete the online survey. All cardiac diseases were included with the exception of a primary diagnosis of hypertension or preeclampsia.

8.4.3 Data collection and instrument

The MGI is adapted from the Patient-Generated Index individualised QoL instrument to be applicable for mothers and to date has been used in pregnancy and the postpartum period (Symon et al., 2002). The instrument is primarily quantitative with possible qualitative analysis and it has been validated in various languages and transcultural applications (Grylka-Baeschlin et al., 2015; Hendrych Lorenzová et al., 2019; Symon, McGreavey, et al., 2003). The MGI is a respondent-driven subjective tool in which the mother determines the content, rather than responding to preformulated questions. With scant data on the experiences of women with CDPP, and the absence of an established set of patient-reported QoL outcomes for CDPP, the MGI enabled the women to nominate the areas of life that were most important to them. In our modification we asked women to respond from the perspective of being a mother with cardiac disease.

Consisting of a three-step questionnaire the MGI can be conducted as an interview or independently completed by participant; we administered the MGI as part of a larger on-line survey. The instruction for Step 1 was modified from asking the women to "*think of the most* *important areas of your life that have been affected by having a baby*" to "*think about the most important areas of your life that have been affected by having a baby as a woman with a cardiac condition*".

8.4.4 Procedure

In Step 1 the woman identifies up to 8 areas that have been most important areas of her life that have been affected by having a baby *as a woman with a cardiac condition*. Each area is then rated as positive, negative, or both/neither. In Step 2 the woman gave a score out of 10 for each of the areas from Step 1 according to how she felt about the issue (area) in the previous month; this produces the Primary Index quality of life score (range of 0 for the worst to 10 for the best possible or optimal). For Step 3 the woman had a total of20 spending points to allocate to each area from Step 1, allocating more points to the areas deemed most important. The allocation of points enables healthcare professionals to understand women's perspectives and priorities. The total points spent in Step 3 must add up to 20.

8.4.5 Data analysis

Descriptive statistics computed were frequency, percentages, mean, and standard deviation. The areas of women's lives that have been affected since having a baby as a woman with cardiac disease were coded into domains and subdomains by two researchers (JH, JF).

The Primary Index is the mean of the scores for Step 2 (Step 2 scores are totalled per woman, then divided by the number of areas she nominated). The Secondary weighted Index is calculated by multiplying the Step 2 score by the Step 3 spend, then totalling for each woman and then divide by the total of the spend. The Primary Index reflects global quality of life, while the Secondary Index quantifies the relative importance of the areas nominated by the woman.

8.5 Results

The women had a variety of acquired (12), congenital (9) and genetic heart disease (4) including; cardiomyopathies, rhythm disorders, coronary artery dissection and myocardial infarction, structural anomalies and valvular conditions. Timing of diagnosis of the cardiac condition ranged from diagnosis at birth through to 12 months postpartum: diagnosed before pregnancy (11), during pregnancy (2) and up to one year postpartum (12). Mean age at time of first CDPP 32 years (range 21 to 39 years). Mean time since the first pregnancy with CDPP was 5 years (range; less than 1 year to 16 years).

Table 8.1*: Rating of nominated MGI areas*

	Total areas	**Relative frequency**	**Spending points allocated**
Positive areas	26	17.9%	22.8%
Negative areas	82	56.6%	53.8%
Both/neither areas	37	25.5%	23.4%

Of the areas of mothering with CDPP nominated by the participants 56.6% (82/145) were negative, 25.5% (37/145) were both/neither, and 17.9% (26/145) were positive (see *Table 8.1*). The areas were categorised into 9 domains. *Table 8.2* reports the number of areas per domain, the mean scores and points spent per domain, and the distribution of rating as positive, negative or both or neither. The domains of 'mothering', 'relationships', and 'physical health' accounted for 87 of the 145 responses (60%). The domain of 'relationships' included 16 comments about her partner/husband and 8 comments about family and friends and it was the only domain with positive as the most common rating (10/24, 41.7% positive), with mean positive responses 9.4/10 (SD 0.8). Relationships also had the lowest mean for negative responses 2.3/10 (SD 0.9).

The domain 'mothering' had the most areas nominated (41); 25 were negative, 9 were both/neither and 7 were positive. The overall mean score for mothering was 5.1/10 (SD 2.8). The positive responses for 'mothering' had the highest mean for any domain (9.7/10, SD 1.7) and the second lowest negative responses (3.6/10, SD2.0). The most common area was feelings about being a good enough mother (21 responses) which was also the most frequently reported area for the whole study. Other areas were her relationship with her child, concern about her child's future and health, wanting more children and issues relating to pregnancy, birth and breastfeeding.

Four domains had zero positive areas and had low overall means: 'religion' (mean 3.0), 'mental health' (mean 3.6), 'career and finances' (mean 3.6) and 'physical health' (mean 3.9). The key concerns for physical health related to the impact of their cardiac condition on their physical capacity and managing those limitations. The remaining domains of 'outlook', 'health management’ and ‘feelings about self’ were comprised of positive, negative and both/neither responses.

Table 8.2: *Mother-Generated Index domains, mean scores and points spent*

Domains	**All areas**			**Positive areas**			**Negative areas**			**Neither/both areas**		
	n	Mean score (SD)	Mean spend (SD)	n	Mean score (SD)	Mean spend (SD)	n	Mean score (SD)	Mean spend (SD)	n	Mean score (SD)	Mean spend (SD)
Mothering	41	5.1 (2.8)	3.7 (2.4)	7	9.7 (1.7)	5.3 (2.4)	25	3.6 (2.0)	2.3 (2.1)	9	5.4 (1.2)	5 (1.9)
Relationships	24	6.3 (3.1)	3.8 (3.1)	10	9.4 (0.8)	4.6 (1.6)	6	2.3 (0.9)	4.7 (4.9)	8	5.4 (1.5)	2.3 (1.8)
Physical health	22	3.9 (2.4)	2.5 (1.7)				16	3.4 (2.2)	2.6 (1.7)	6	5.3 (2.4)	2.2 (1.7)
Outlook	13	7.1 (2.6)	4.9 (3.1)	5	9.4 (0.8)	3.8 (1.6)	6	4.8 (2.2)	6.5 (3.7)	2	8.0 (0.0)	3.0 (0.0)
Health management	13	4.6 (2.4)	3.5 (2.8)	1	8.0 (0.0)	1 (0.0)	9	3.2 (1.2)	3.2 (2.9)	3	7.7 (1.2)	5.3 (1.9)
Feelings about self	11	4.4 (2.3)	3.7 (2.5)	3	7.3 (1.9)	3.7 (0.9)	6	3.0 (1.2)	4 (3.2)	2	4.0 (1.0)	3.0 (1.0)
Mental health	11	3.6 (1.7)	3.1 (2.0)				8	3.4 (1.5)	3.4 (2.2)	3	4.3 (1.9)	2.3 (0.9)
Career & finances	9	3.6 (1.4)	2 (0.9)				5	2.8 (1.3)	2.4 (1.0)	4	4.5 (0.9)	1.5 (0.5)
Other (religion)	1	3	3				1	3	0			

Table 8.3: *MGI Primary and Secondary Index*

	Total	**Mean (SD)**
Primary index	120.3	4.8 (1.5)
Secondary index	134.3	5.4 (2.1)

The mean Primary index score was 4.8 (range 2.5 to 7.8) and the mean Secondary index was 5.4 (range 2.3-10), as in Table 8.3. Women identified on average 5.8 areas of importance (range 2-8). total of 15 (60%) women had a Primary MGI score of 5 or less which is associated with poorer physical and psychological health (Symon, MacKay, et al., 2003; Symon, McGreavey, et al., 2003). Three of the four lowest mean primary scores (mean 2.7, SD 0.1) were observed in women whose CDPP was diagnosed postpartum. Three of the four highest mean primary scores (mean 7.0, SD 0.5) were observed in women diagnosed before pregnancy.

8.6 Discussion

The use of the MGI enabled women to nominate for themselves the areas of their lives that were of most importance to them; mothering, relationships, and their physical health. Motherhood and illness lead to a re-modelling of self-identity (Asbring, 2001; Charmaz, 1983; Wisdom et al., 2008) and parenthood brings changes to intimate relationships (Lambermon et al., 2020) which can be positive or negative (Hjälmhult & Lomborg, 2012). This is confirmed in our finding that mothering and relationships were the two most identified areas in the MGI, with relationships the only domain with positive as the most common rating. When scored as a positive, mothering and relationships scored the highest and second highest and second highest respectively for mean spend. Women who scored relationships as a negative allocated the second highest spend for negative (reflecting perceived importance of the issue); in contrast women who scored mothering as a negative, allocated the lowest spend to it. The importance of relationships in this study and the relative lack of it in our earlier qualitative study using interviews (under review) may confirm observations that anonymous online surveys can be valuable in collecting potentially sensitive qualitative data, such as negative feelings about one's partner (Braun et al., 2020). In addition, responses highlighted that partners of women with CDPP can experience their own trauma, grief and challenges through their experiences and require support themselves (Hinton et al., 2015b; Patel et al., 2019)

This is the first study to our knowledge that uses the MGI to evaluate women's QoL as mothers with CDPP (or other chronic illness). Moreover, it is unique in capturing data for women with pre-existing cardiac disease as well as women diagnosed in pregnancy or the first year postpartum, and for women with a diversity of cardiac conditions. Further, it is the first study to examine women's experiences beyond the early postpartum period, with the average length of time since participants CDPP being 5 years 8 months, thereby providing a perspective absent in the literature about the enduring impact of the intersection of CDPP and mothering.

Our research adds to the literature on women with CDPP with new findings of women's focus on the longer-term outlook, especially *"staying alive long enough to raise their children"*, and their reduced career options and financial security. The desire to survive and raise their children was concurrent with the findings of the negative feelings the women have about themselves as mothers, reflecting the complexity of CDPP and associated risks of depression and poorer cardiac outcomes.

As with other aspects of CDPP, there is a paucity of research on QoL, especially related to mothering, despite the increasing prevalence of CDPP and its associated morbidity, mortality. Patient reported outcomes measures (PROMs) quantify patient's perceptions of their health and functional status, independent of interpretation by HCPs or researchers (Dawson et al., 2010; Field et al., 2019). Patient-reported anxiety, depression, perceived health, QoL and distress are independent predictors of subsequent hospital readmission and costs, morbidity and mortality, and knowledge of these factors can aid in risk assessment and resource development and allocation (Rumsfeld et al., 2013; Vámosi et al., 2020). Disease-specific PROMs are optimal (Algurén et al., 2020) and while there are multiple instruments available for various cardiac diseases (Thompson et al., 2016), and for pregnancy and postpartum (Mogos et al., 2013), at present there are no validated PROMs specific to individual or combined cardiac diseases in pregnancy and postpartum. A few studies have adapted existing instruments to fill this gap (Koutrolou-Sotiropoulou et al., 2016). Of the limited data available on patient-reported outcomes for women with CDPP most prevalent were findings of poorer mental health and lower QoL outcomes (Koutrolou-Sotiropoulou et al., 2016).

In an environment of limited research on CDPP, patient-reported outcomes offer an opportunity to enhance researcher and clinician knowledge, clinical outcomes, and QoL for women, including their experiences mothering. PROMs enable patients to describe issues or respond to questions about issues that are not usually discussed in routine clinical care assisting them to highlight unmet needs, such as issues identified in this research of partner relationships, sex, death and concerns about their children (Greenhalgh et al., 2018; Higginson & Carr, 2001; Kane et al., 2018; Lavallee et al., 2016; Thompson et al., 2016). Completing the PROM as an anonymous survey, such as with this research, may facilitate greater disclosure of sensitive subjects, or of feelings one might not feel able to disclose in an interview (for example, not feeling like a good enough mother, or negative feelings about one's partner) (Braun et al., 2020).

A recent content comparison of 34 cardiac disease PROMs found a preponderance of PROMS related to physical and emotional functions, with no explicit mention of issues related to parenting or mothering which was paramount for the women in our study, or items relating to career (Algurén et al., 2020). Similar findings have been reported for pre-eclampsia (Duffy et al., 2019). A systematic review of research on cardiac disease in pregnancy found 94% of studies reported only on clinical or adverse effects and none included PROs on QoL impact and functioning (Hall & D'Souza, 2020). However, pregnant women with cardiac disease want QoL included as a PRO and this should be incorporated alongside the more clinically based outcomes (Hall & D'Souza, 2020; Parsonage et al., 2020). The use of the MGI in this research enabled women to nominate the areas that were important to them; this has produced unique findings and validates the use of this PROM.

8.7 Limitations and strengths

This is the first study exploring women's experiences and QoL as mothers across a spectrum of CDPP, enabling the inclusion of women with rare diseases who otherwise may not be included in research due to small numbers. Use of the MGI produced novel results as the women determined the themes. There was no specific measure to ensure diversity with findings limited to English-speaking women; the majority of interviewees were recruited via social media therefore women not using social media were unlikely to be included in this study. More studies are needed to understand specific needs of women with CDPP, including the needs of diverse populations and changing needs over time

8.8 Conclusion

Modifying the MGI to be specific to mothers with CDPP provided a unique opportunity for women to nominate the areas of importance to them. This research revealed the largely negative impact of CDPP on women's quality of life across a variety of domains including their experiences of mothering, fears of reduced longevity, advice to have no more children and to cease breastfeeding, the physical limitations imposed by their condition, and managing their health. However, their experiences of their relationships were predominantly positive. Women's experiences were complex and persisted well beyond pregnancy and the first year postpartum, indicating a need for enhanced chronic care, rehabilitation and counselling support.

8.9 Chapter summary

This chapter identified that the mean quality of life score for women with CDPP was less than 5, which is associated with poorer physical and psychological wellbeing. CDPP affected women's lives in multiple domains, which were mostly experienced as negative. Women's experiences were complex and the issues of having CDPP continued well beyond pregnancy and the first year postpartum. In addition, this chapter reports on the first use of the MGI for women who have acute and chronic health conditions, and included participants with a range of conditions, and experiences of CDPP which were very recent through to 16 years prior, indicating a possible broader application of this instrument in future research.

Chapter 9: Quality of life and mental health of women who had cardiac disease in pregnancy and postpartum

9.1 Publication

The results of this section have been published as follows:
Hutchens, J., Frawley, J. & Sullivan, E.A. (2022). Quality of life and mental health of women who had cardiac disease in pregnancy and postpartum. *BMC Pregnancy Childbirth 22*, 797.

9.2 Chapter introduction

This chapter provides the findings of quantitative assessments of the quality of life (QoL) and mental health of women with cardiac disease in pregnancy and the first year postpartum (CDPP), answering thesis research Question 2 *"What is the impact of having CDPP on women's mental health?"* and Question 4 *"What is the impact of having CDPP on women's quality of life?"* Analysis of the qualitative study found that negative mental health was a significant outcome for women, as described in depth in Chapter 6, and included in all other chapters above. Women's quality of life as mothers with CDPP was examined in the previous chapter. This chapter uses global and specific patient-reported outcome measures to provide further analysis and quantification of mental health and QoL.

9.3 Background

Cardiac disease complicates 1-4% of pregnancies and is a lead cause of maternal morbidity and mortality in low- and high-income countries (Regitz-Zagrosek et al., 2018). Prevalence data for cardiac disease in the first 12 months postpartum is less defined, however overall prevalence in pregnancy and postpartum is increasing (Balgobin et al., 2020; Regitz-Zagrosek, 2019). Cardiac disease in pregnancy and postpartum (CDPP) encompasses a disparate range of acquired, congenital and genetic conditions. Women with CDPP have a higher risk of poor quality of life (QoL) and mental health outcomes due to the concurrence of multiple factors relating to particular cardiac factors and personal characteristics. Cardiac factors include: the association of cardiac disease with poorer mental health (A. K. Johnson et al., 2020; Vilchinsky et al., 2017), prognostic uncertainty, cardiac disease and lower QoL (Aggelopoulou et al., 2017), and the specific challenges experienced by adults with congenital heart disease (Malik et al., 2021) and younger people with cardiac disease in general (Journiac et al., 2020). Personal characteristics that reduce QoL include: the presence of pre-existing and perinatal mental health conditions (Woody et al., 2017), the effects of maternal near-miss events (Soma-Pillay et al., 2018), and the experience of mothering with a chronic illness (de Wolff et al., 2018; Power et al., 2015). These associations have mental health and QoL implications however, they are yet to be fully examined.

Disease-specific PROM tools are optimal (Algurén et al., 2020) and while there are multiple tools available for various cardiac diseases (Thompson et al., 2016), and for pregnancy and postpartum (Mogos et al., 2013), at present there are no validated PROMs specific to individual cardiac diseases in pregnancy and postpartum. A few studies have adapted existing tools to fill this gap (Koutrolou-Sotiropoulou et al., 2016).

Patient reported outcomes measures use standardised, validated patient-completed questionnaires to quantify patient's perceptions of their health and functional status, independent of interpretation by healthcare professionals (HCPs) or researchers (Dawson et al., 2010; Field et al., 2019). Patient reported outcomes are essential in understanding and improving clinical and broader QoL outcomes and are integral to person-centred care and shared decision-making (Rumsfeld et al., 2013). Patient-reported anxiety, depression, perceived health, QoL and distress is an independent predictor of subsequent hospital readmission and costs, morbidity and mortality, and knowledge of these factors can aid in risk assessment and resource development and allocation (Rumsfeld et al., 2013; Vámosi et al., 2020).

Of the limited data available on patient-reported outcomes for women with CDPP most prevalent were findings of poorer mental health and lower QoL outcomes (Koutrolou-Sotiropoulou et al., 2016). It has also been reported that anxiety (generalised and cardiac-specific) and reduced quality of life persist up to 10 years after women's CDPP (Rosman et al., 2019). Further, women with CDPP are at an increased risk of being diagnosed with a major mental health disorder (Pfeffer et al., 2020) as a consequence of their illness and score almost twice as high for anxiety and depression as non-pregnant women and men with the same cardiac condition (F. Légaré et al., 2018; Liang et al., 2014).

This exploratory study sought to understand the QoL and mental health for women who had cardiac disease in pregnancy and the first year postpartum in Australia. Understanding these women's experiences will guide further research and provide important data for clinicians and healthcare services to improve the lives of women with CDPP.

9.4 Methods

9.4.1 Study protocol and participants

This exploratory descriptive study was developed in response to a previous qualitative study by the authors that identified ongoing reduced QoL and mental health challenges for women who had CDPP (Hutchens et al., 2022). Data for the present study were collected from an anonymous online survey using the Qualtrics Software (Nov 2021) and analysed using IBM SPSS Statistics for Windows, Version 28.0. Ethics approval was granted by the University of Technology Sydney's *Human Research Ethics Committee.*

Participants were recruited via Facebook and cardiac organisations from August to November 2021. Participation was voluntary and did not attract any financial benefit. A detailed description of the study was provided, and consent was confirmed by commencing the survey. Inclusion criteria were Australian residents or citizens who were living in Australia when they had cardiac disease during any pregnancy or in the first 12 months postpartum and who gave birth to one or more babies beyond 20 weeks' gestation or 400gm or greater birthweight; were 18 years of age and older and who had sufficient English language skills to understand this information and complete the survey. All cardiac diseases were included excluding a primary diagnosis of hypertension or preeclampsia.

9.4.2 Measures

The following survey instruments were used to capture a breadth of data on this under-researched population.

WHOQoL-Bref

The WHOQoL-Bref was chosen as the generic QoL instrument because its theoretical construct is based on a broad concept of QoL and health that is not limited to biomedical aspects. The WHOQOL-Bref is a well-established validated tool, used in studies on a variety of physical conditions such as CHD (Areias et al., 2013), postpartum (Webster et al., 2010), rheumatoid arthritis (Taylor et al., 2004), depression (Amir & Ramati, 2002), posttraumatic stress disorder (Johansen et al., 2007) and anxiety and stress (Rusli et al., 2008).

The Australian WHOQoL-Bref questionnaire is an abridged version of the WHOQoL-100 (Murphy et al., 2000). It contains 2 global questions (overall QoL and health satisfaction) and 24 questions divided into four domains: Domain 1 physical health (7 items), Domain 2 psychological health (6 items), Domain 3 social relationships (3 items) and Domain 4 environment (8 items). For this study we excluded Q26 "How often do you have negative feelings such as blue mood, despair, anxiety, depression?" due to repetition with other instruments in the study, leaving 5 items in Domain 2 (psychological health). Each item is rated on a 5-point Likert scale. The raw domain scores are scaled in a positive direction and transformed to a 0-100 scale for comparison with WHOQoL-100. The two global questions are scaled in a positive direction with a score range of 1-5. Higher scores for both the domains and the global questions indicate higher QoL. Domain scores were calculated according to the Guide and transformed to be out of 100 (Bulk et al., 2019). Cronbach's Alpha was used to demonstrate internal consistency of the WHOQoL-Bref scale (.921).

Modified Kansas City Cardiac Questionnaire (KCCQ)

The KCCQ is a health related QoL (HRQoL) instrument for individuals with heart failure that quantifies the domains of physical limitations, symptoms, self-efficacy and knowledge, social interference, and QoL (Green et al., 2000; Spertus & Jones, 2015). The KCCQ focus is on the presence, severity, and impact of heart failure symptoms on functionality. Item responses are coded sequentially (e.g., "not at all satisfied" to "completely satisfied") from worst to best status. We have incorporated adaptations to the KCCQ by Koutrolou-Sotiropoulou et al. (2016) relating to work status, counselling and future pregnancies. These items were coded on a scale, and some also included free text sections.

The cardiac HRQoL was augmented by including modified questions relevant to mothers and younger patients such as concerns regarding longevity, their children, finances, sex and access to care from an recent study on women with peripartum cardiomyopathy (PPCM) (Rosman et al., 2019). Our study included women with a diversity of cardiac diagnoses so the above cardiac HRQoL tools were modified to be applicable for all participants. Novel questions were developed to distinguish between information and counselling provided at time of diagnosis, rate the quality of information and communication, determine if counselling was provided in response to advice to avoid having further children and what impact that advice had on participants, and frequency of missing medical appointments due to cost. These new questions were developed after our qualitative study which found a lack of recognition of the mental health impact of CDPP in both the short and long term, and subsequent lack of mental health referral or support provided (Hutchens et al., 2022). Affirmative responses to scaled questions were consolidated to a single positive response (e.g., a little, moderate, very) for the purpose of analysis. Cronbach's Alpha was used to demonstrate internal consistency of the KCCQ scale (0.919).

Both the WHOQoL-Bref and the KCCQ include measures more accurately described as measures of disability, or limitation, such as ability to walk around the block, and these are possibly more applicable to an older population (A. J. Carr et al., 2001; Higginson & Carr, 2001). Most of these types of questions were retained to facilitate comparison of results. Additional questions introduced by Koutrolou-Sotiropoulou et al. (2016) measured clinical outcomes such as ejection fraction and medication use rather patient-reported outcomes therefore they were not included in this study as they were not patient centred.

Depression, Anxiety, and Stress Scales-21 (DASS-21)

The DASS-21 is a validated self-report scale with three subscales of depression, anxiety, and stress (P. F. Lovibond & S. H. Lovibond, 1995; S. Lovibond & P. Lovibond, 1995). The DASS-21 was chosen as the general mental health instrument as it differentiates between depression, anxiety and stress, is short and simple to complete, and is a key tool used in research, general practice and mental health services in Australia (Crawford et al., 2011).

The depression subscale items focus on low mood, hopelessness, low self-esteem, ability to feel pleasure and inertia. The anxiety subscale items focus on physiological arousal, situational anxiety, and feelings of panic and fear. The stress subscale items focus on difficulty in relaxing, impatience, irritability, and chronic non-specific arousal. Each subscale has 7 items, all answered on a Likert scale from 0 (“Did not apply to me at all'') to 3 (“Applied to me very much, or most of the time'') (S. Lovibond & P. Lovibond, 1995; Shea et al., 2009). The scores for the total DASS-21 and for each subscale are summed, with low scores reflecting better mental health. Cronbach’s Alpha was used to demonstrate Internal consistency of the DASS-21 scale (0.908).

Cardiac Anxiety Questionnaire (CAQ)

The CAQ was used as a specific assessment of cardiac anxiety, which is apprehension and fear related to cardiac-related stimuli and sensations (Eifert et al., 2000). The CAQ has 18 items with 3 subscales of fear (8 items), avoidance (5 items), and heart-focused attention (5 items). Each item is rated on a 5-point rating scale from 0 (“never”) to 4 (“always”). The total score is calculated as the mean of all items. Subscale scores are calculated as the mean of the relative frequency ratings for each of the items in each subscale. There are no validated clinical cut-off scores however according to the grading of the items, a higher total and subscale scores indicate greater cardiac-related anxiety (Eifert et al., 2000; Hoyer et al., 2008). Cronbach’s Alpha was used to demonstrate Internal consistency of the CAQ scale (0.852).

9.4.3 Analysis

Data were summarised using descriptive statistics and included frequencies and percentages for categorical data, with ranges, means, and standard deviations for continuous data. Validated instruments were scored according to the requirements of each instrument. Data were considered based on time since CDPP (< 5 years or > 5years) and combined category of disease (acquired or combined congenital and genetic heart disease.

9.5 Results

9.5.1 Participant characteristics

A total of 43 women completed the survey. Women reported a range of acquired, congenital and genetic conditions, including; cardiomyopathies, rhythm disorders, coronary artery dissection and myocardial infarction, structural anomalies and valvular conditions (see *Appendix A*). Timing of diagnosis of the cardiac condition ranged from birth through to 12 months postpartum. Mean age at the time of first CDPP was 31.39 years (19-39), mean time since the first pregnancy with CDPP was 4.9 years. See *Appendix B* for participant characteristics.

9.5.2 The WHOQoL-Bref

The transformed score out of 100 for overall QoL was 80.8 +/-21.7 and health satisfaction and 51.7 +/- 25.2. WHOQoL-Bref results are outlined in *Table 9.1*.

Table 9.1: *WhOQol-Bref scores*

	Score	SD +/-
Overall QoL	80.8	21.7
Health satisfaction	51.7	25.2
Physical health	55.2	11.9
Psychological health	64.9	17.1
Social relationships	63.0	22.1
Environment	72.2	21.7

Health satisfaction was scored as “very dissatisfied/dissatisfied” for 37.5% of participants whose CDPP was less than 5 years ago, and 35% of those whose CDPP was more than 5 years ago. While significance is difficult to determine due to the sample size, it is worth noting the continued dissatisfaction with their health for 35% of participants who experienced CDPP more than five years prior to the survey.

9.5.3 KANSAS and additional questions

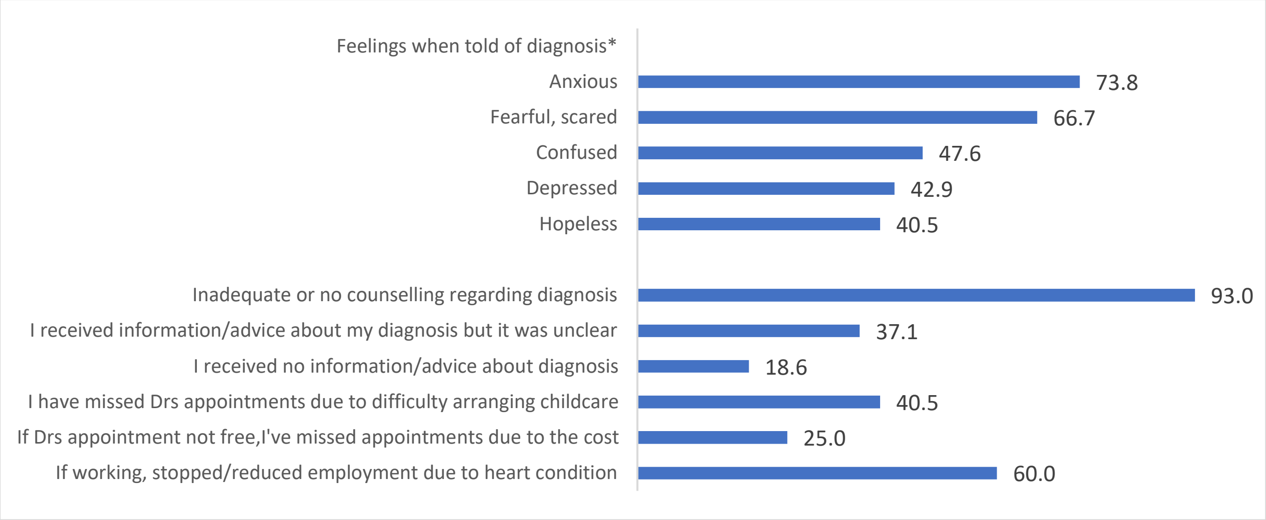
WHOQoL-Bref scores QoL as a single question and the KCCQ QoL is a composite score of 3 questions; both are scored out of 100. The mean WHOQoL score for overall QoL was 84.6, compared to the mean HRQoL score from the modified KCCQ of 63.1. Domain results of the modified KCCQ are outlined in *Table 9.2*.

Table 9.2: *Modified KCCQ scores*

Quality of life	63.1
Physical limitation	72.6
Self-efficacy	75.5
Symptoms	73.2
Social limitations	79.1

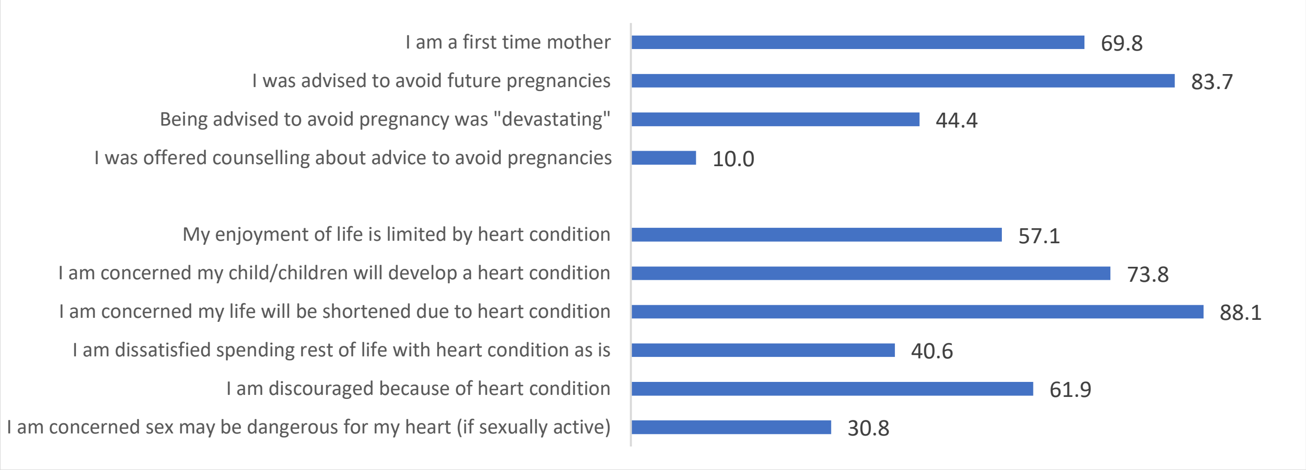
Key results for the combined cardiac HRQoL questions are shown in *Figures 9.1 and 9.2*. The majority of women were advised to avoid future pregnancies which 88.9% scored as "upsetting" through to "devastating" with 10.0% offered counselling. Concern about reduced life expectancy due to heart condition was high (total 88.1%) and was not fully moderated by time, with 40% of women who had CDPP in the past 18 months and 48.4% who had CDPP 18 months or longer ago scoring "very concerned". Many women worried about their children developing a cardiac condition (73.8%). Women were at times unable to attend medical appointments due to cost (25.0%) and difficulty arranging childcare (40.5%). A summary of key results of the combined cardiac HRQoL are summarised in Figure 9.1 and Figure 9.2.

Figure 9.1: *Communication, access and support*



* Or was old enough to understand diagnosis

Figure 9.2: *Key concerns*



9.5.4 DASS-21

Depression was scored as “moderate”, “severe” or “extremely severe” for 24% of participants, anxiety 22% and stress 19.5%. Women diagnosed during pregnancy had the highest scores for depression (50.0%) and stress (33.4%) and women diagnosed before pregnancy scored highest for anxiety (28.5%). By category, women with acquired heart disease scored highest for depression (30.4%) and stress (26.1%), and women with congenital heart disease scored highest for anxiety (36.4%). Core Dass-21 results are provided in *Table*

9.3 and *Table 9.4*. It is noted that it is difficult to determine significance with small sample size.

Table 9.3: *DASS-21 scores*

	Mean	Std deviation
Depression	4.29	3.82
Anxiety	3.41	2.89
Stress	6.27	3.83
Total DASS	13.98	9.20

Table 9.4: *DASS-21 scores for category of disease and time since CDPP*

	Acquired		CHD/genetic				<5yrs since diagnosis		>5yrs since diagnosis			
	n	%	n	%	p =	Total	n	%	n	%	p =	Total
Anxiety												
Yes	5	22%	4	22%	.970	9	6	25%	3	19%	.643	9
No	18	78%	14	78%		32	18	75%	13	81%		31
	23		18			41	24		16			40
Depression												
Yes	7	30%	3	14%	.308	10	7	30%	3	19%	.456	10
No	16	70%	15	86%		31	17	70%	13	81%		30
	23		18			41	24		16			40
Stress												
Yes	6	26%	2	11%	.230	8	6	25%	2	12%	.330	8
No	17	74%	16	89%		33	18	75%	14	88%		32
	23		18			41	24		16			40

9.5.5 Cardiac anxiety questionnaire

The total CAQ score was 34.6 +/- 10.217. Of the subscales, fear (1.86) and avoidance (1.67) are lowest and heart-focused attention (1.87) is highest in those diagnosed before pregnancy. By disease category fear was highest for women with acquired heart disease (2.10), avoidance highest in genetic (2.09) and lower for CHD (1.47) and heart-focused attention highest in CHD (1.84). The highest scoring individual item was "I pay attention to my heartbeat" (71.4%). Core CAQ results are provided in *Table 9.5*.

Table 9.5: *Cardiac anxiety questionnaire scores*

	Mean	Std. deviation
Fear	2.00	0.612
Avoidance	2.02	0.877
Heart focused attention	1.71	0.729
Overall	1.92	0.568

9.6 Discussion

There is a paucity of research into the QoL and mental health of women who have had CDPP, despite the increasing prevalence of CDPP and its associated morbidity, mortality. In this exploratory study we describe the QoL and mental health of women who had CDPP in Australia. Our novel findings include: 1) the primacy of issues relating to motherhood, mothering and children, 2) the need for and lack of mental health support, 3) a substantial difference in the generic QoL compared to the HRQoL, 4) poor outcomes for HRQoL, health satisfaction and mental health, 5) poor QoL and mental health outcomes did not necessarily improve with time since diagnosis.

Our study found that the mean for overall QoL in the WHOQoL-Bref was comparable to Australian norms, however health satisfaction was lower for women with CDPP (Murphy et al., 2000). The WHOQoL-Bref domain scores were markedly lower than norms for similarly aged females, in particular for the domains of physical health, (55.2 vs 80.3), psychological (64.9 vs 73.6) and social relationship (63.0 vs 74.8) (Hawthorne et al., 2006).

Women scored themselves lower for QoL on the modified KCCQ HRQoL as opposed to the generic WHOQoL-Bref. This may be due to specific questions related to cardiac function on the HRQoL scale, suggesting disease-specific measures may be more sensitive and better able to pick up subtle changes and impacts. Higher levels of other social and environmental determinants of health that influence QoL such as housing security, and access to healthcare (most people in Australia can access universal healthcare) may affect this score or the HRQoL may be more sensitive to the issues pertinent to participants as it a specific cardiac QoL tool. The majority of research using the KCCQ is with older individuals with heart failure and include clinical and treatment outcomes, precluding comparison with our cohort of childbearing women (Ravera et al., 2021). Individuals with low QoL and HRQoL have an increased for further cardiac events and increased mortality risk (Barofsky, 2011; Idler et al., 2004).

The scores for QoL and the domains did not necessarily improve substantially over time, reflecting the chronicity of CDPP, and that support and services need to continue beyond standard perinatal timeframes of six weeks postpartum. Further, this suggests the need for longitudinal studies of women who experience CDPP. Nearly three-quarters of women surveyed were anxious about their children developing a heart condition; this likely reflects understanding of the condition and the level of information and genetic counselling provided.

Clinically significant levels of anxiety and depression were scored for both the DASS-21 and the CAQ. DASS-21 scores for the total and three subscales of depression, anxiety and stress were higher than all-age Australian norms (13.98 vs 8.30, 4.29 vs 2.57, 3.41 vs 1.74 and 6.27 vs 3.99 respectively) (Crawford et al., 2011). Participants were twice as likely to score at least moderate anxiety on the CAQ (45%) compared to the DASS-21 (22%) which may reflect sensitivity and or specificity of heart-related anxiety compared to general anxiety. The total and domain scores for the CAQ were comparable to Rosman's study of women with peripartum cardiomyopathy (Rosman et al., 2019), and notably higher than studies on cardiac patients in general (Christoph et al., 2014; Eifert et al., 2000) and people presenting to the emergency department with non-cardiac chest pain (Mourad et al., 2016). The scores were decidedly higher than norms for women of a similar age range who didn't have cardiac disease (Fischer et al., 2011). The CAQ subscale of avoidance may indicate heart-related anxiety, or it may reflect appropriate self-management and following medical advice, and this is worth further examination. Questions relating to interactions with HCPs and access to healthcare

are also noteworthy, reflecting anxiety about their health and management by health professionals. Importantly, cardiac anxiety, depression and other mental health conditions are associated with increased risk for further cardiac events and mortality (Maria H. C. T. van Beek et al., 2016), in particular, in women (O'Neil et al., 2021). These responses suggest a need for improved information and knowledge sharing, skill development and counselling (M. H. C. T. van Beek et al., 2014).

Our results are consistent with related cardiac, mental health and maternal health research. Being female is associated with an increased risk for anxiety and depression in a variety of cardiac conditions and is associated with increased health utilisation, morbidity and mortality (Benderly et al., 2019; Gleason et al., 2019; Liang et al., 2014). Further, individuals living with conditions associated with sudden cardiac death, such as Long QT Syndrome are at increased risk of anxiety, fear, depression and lower QoL (Hamang et al., 2011; James et al., 2012; O'Donovan et al., 2020). Adults with implantable cardioverter defibrillators (ICDs) are reported to have higher anxiety in general and specifically shock-related anxiety and this is associated with lower sexual functioning scores, another important aspect of QoL (Cook et al., 2013). Individuals living with genetic cardiac conditions are at risk of lower HRQoL, and higher levels of anxiety and depression compared with population norms (O'Donovan et al., 2020). In addition, experiencing depression, including postpartum depression is associated with lower QoL, physical satisfaction and mental health scores (Papamarkou et al., 2017). QoL and anxiety and depression may be modifiable with improved communication, psychological interventions and support, increased knowledge and genetic counselling as indicated (Hamang et al., 2011; O'Donovan et al., 2020).

In an environment of limited research on CDPP, PROs offer an opportunity to enhance researcher and clinical knowledge, clinical outcomes, and QoL for women. Using PROMs can lead to better symptom recognition which is especially relevant as cardiac disease is under-recognised and under-reported in females (Etkind et al., 2015; Jin et al., 2020; Norris et al., 2020). PROMs enable patients to describe issues or respond to questions about issues that were not usually discussed, assisting them to highlight unmet needs (Greenhalgh et al., 2018; Higginson & Carr, 2001; Kane et al., 2018; Lavallee et al., 2016; Thompson et al., 2016). The use of PROMs may prompt different communication approaches and content, leading to greater exchange of information, improved relationships, greater referrals, and co-ordination of care, as well as increased person-centred care (Chen et al., 2013; Lavallee et al., 2016; Thompson et al., 2016; Velikova et al., 2004). Finally, being involved in providing feedback through PROs is associated with improved psychological outcomes, HRQoL and patient satisfaction (Chen et al., 2013; Etkind et al., 2015; Velikova et al., 2004).

The results of this study indicate all the above characteristics of PROMs are desirable and may address the negative aspects of their PROs; however, this is dependent on the attributes of the PROM. A content comparison of 34 cardiac disease PROMs found a preponderance of PROMS related to physical and emotional functions, with no explicit mention of issues related to parenting or mothering which was paramount for our participants (Algurén et al., 2020). A systematic review of research on cardiac disease in pregnancy found 94% reported only on clinical or adverse effects and none included PROs on life impact and functioning (Hall & D'Souza, 2020). However, pregnant women with cardiac disease want QoL and mental health included as PROs and these should be incorporate alongside the more clinically based outcomes (Hall & D'Souza, 2020; Parsonage et al., 2020). The CDPP-specific questions in our survey were the items that had the strongest responses, highlighting their importance to participants. It is imperative that women with CDPP are involved in future PROM design to capture these issues as well as topics including contraception counselling and use, sexual (dys)function, pregnancy and postpartum, and parenting and to be patient-centred (Alison J. Carr & Higginson, 2001; Neiman et al., 2017; Opić et al., 2013; Rosman et al., 2017; Wiering et al., 2017).

9.7 Strengths and limitations

This study is the first to our knowledge that includes a diversity of cardiac conditions across the three categories of acquired, congenital and genetic heart disease, and the first to include women who were diagnosed up to 12 months postpartum. This extended timeframe is particularly relevant for pregnancy-associated spontaneous coronary artery dissection and peripartum cardiomyopathy where late cases are diagnosed up to a year postpartum. In addition, we included a diversity of PROMs to capture a broad range of data and developed new questions that revealed important outcomes for women with CDPP. Participants had their first pregnancy affected by CDPP on average 5 years prior to completing the survey and this provides a useful longer-term perspective, and the reported prevalence of negative

HRQoL and mental health outcomes highlights the persistence of issues related to CDPP. In addition, surveying patients close to a health event can lead to a distortion of results with survival gratefulness and optimism being overstated, and the effects of attempting to re-enter life, resume normal functions, work and social interactions, and in the case of CDPP, embark on mothering with a cardiac condition, may not yet be fully realised and thus unable to be captured at this early stage (Åberg, 2020).

There are also clear limitations to this descriptive study. Recruitment was limited to those using Facebook or on mailing lists of cardiac organisations and registries, and recruited numbers were below what was required to perform further statistical analysis and to be considered representative. We did not record disease severity which is associated with degree of QoL impairment (Kahr et al., 2015). Additional topics that would be valuable to examine but were not included are those relating to breastfeeding and having difficulty due to chest wall surgery or being advised to cease breastfeeding due to cardiac medications, the impact on sexual relationships, and the specific issues associated with treatments (e.g., ICDs). Further, it is noted that some women's rating of experiences relates to healthcare episodes many years ago, and may be affected by recall bias or services may have changed since that time. These limitations notwithstanding, there are important strengths in understanding women's experiences, and these provide weight for arguing for a better healthcare experience informed by evidence-based research.

9.8 Recommendations

- Women centred research co-designed with consumers to inform person-centred care and improve QoL and mental health outcomes.
- Co-designed research into the mental health and QoL impacts on partners and children of women with CDPP.
- Co-development of patient-centred PROMs for CDPP (beyond clinical maternal and cardiac outcomes); including mothering, relationships, breastfeeding, fertility.
- Longitudinal studies with multiple timepoints, with adequate representation from each category and severity of cardiac disease.
- Funded cardiac research to include in all analytic plans sex disaggregated data and for women of reproductive age pregnancy/postpartum status.

9.9 Conclusion

This study found women with CDPP had reduced QoL and mental health outcomes which was not necessarily ameliorated over time. This had an additive effect of increased risk of poorer cardiac outcomes and increased health service utilisation. Some differences were noted based on category of disease and timing of diagnosis of CDPP, however longitudinal studies are required to confirm and expand on this. Women need increased support, information, and opportunities to engage as active participants in their healthcare, noting the centrality of being a mother to their experience, identity, and needs.

While in recent years more women are included as participants in research, issues around mothers and mothering remain largely invisible in CDPP research. This has resulted in issues that are relevant to women such as having further children, breastfeeding, contraception, the impact on their ability to mother in the way they want to, fear for the children's cardiac health and their own ability to survive long enough to raise their children not being acknowledged or investigated. This could be addressed in routine clinical care through engaging women with CDPP to develop comprehensive and sensitive disease-specific PROMs. These can be integrated into clinical management and provide an opportunity to characterise women's health and QoL in the longer-term, evaluate the impact of health interventions, and improve outcomes.

9.10 Chapter summary

This chapter has quantified and built on the findings of early chapters relating to QoL and mental health. Women with CDPP reported low health satisfaction, physical health, and HRQoL. They had clinically significant scores for depression (24%), anxiety (22%) and stress (19.5%) (DASS-21) and 44.5% scored at least moderate anxiety on the CAQ. The majority of women reported inadequate information and counselling support, with women with CDPP having sustained impaired QoL and mental health outcomes. The new and modified questions relating to mothering and children reflected the primacy of mothering to women's identity and needs, as well as the necessity of including questions relating to being a mother in future PROMs. The next chapter concludes the research findings and reports on the needs of women with CDPP.

Chapter 10: The needs of women with cardiac disease in pregnancy and the first 12 months postpartum

10.1 Chapter introduction

The aim of this chapter is to answer the final research question *"What are the needs of women with CDPP?"* as outlined in Chapter 1. This chapter provides a summary report on the results of a needs assessment and subsequent focus group with women who experienced CDPP. The information in this chapter has been prepared as a report to the Heart Foundation.

Earlier chapters identified and examined women's experiences across different domains, identifying a range of sub-optimal outcomes and gaps in services. Data analysis of the qualitative interviews conducted as part of this thesis are described in Chapters 4, 5, 6 and 7. Chapter 4 focused on healthcare experiences and produced the key themes of fragmented healthcare services; services being designed for other patient groups and a lack of mother-specific care and resources; lack of research, knowledge and information on the cardiac disease in pregnancy and postpartum; being dismissed by health professionals; and the mental health impacts of their experiences.

Chapter 5 explored self-advocacy in healthcare and analysis generated four central themes: loss of voice and feeling impotent; the challenges self-advocating; fears and the destabilising effect of not having a voice; and finding ways to advocate for themselves and other women and girls. Chapter 6 focused on mental health and produced three major themes: the index event and its emotional and psychological impact; self-perception and identity; and a strong sense of isolation and how the participants attempted to overcome this.

Chapter 7 explores women's experiences mothering with CDPP. The qualitative analysis of the interviews produced the themes describing the importance of being a mother to their sense of self and identity, breastfeeding and being able to make their own decisions about future children, difficulties relinquishing care and the interrupted connection with their children due to illness. Chapter 8 presents the analysis of the Mother-Generated Index which identified the primacy of mothering in their experiences as women with a cardiac condition, and included themes of the importance of relationships, and concerns about their longevity and their children's health. Chapter 8 highlighted that these areas deemed of highest importance were experienced as both positive and negative.

Analysis of the qualitative online survey is described in Chapter 9. Key findings included; the emotional impact of their diagnoses; being advised to have no more children; lack of counselling provided at the time of diagnosis or when they were advised to have no further children; worry about their children; and anxiety about their longevity.

10.2 Background

Cardiac disease in pregnancy and postpartum (CDPP) is a term that includes a range of diseases, such as cardiomyopathy, rhythm disorders, coronary artery dissection and myocardial infarction, structural anomalies and valvular conditions. Individual diseases are rare or uncommon however the international estimated combined prevalence is significant at 1-4% (Regitz-Zagrosek et al., 2018); this translates to between 3,056 and 12,226 Australian women being affected annually (Australian Institute of Health and Welfare, 2020). Despite this prevalence, there is little data on women's experiences or clinical and patient-reported outcomes. Further, there has been no assessment of the resources and support needs of women.

Women with CDPP have complex conditions combined with being pregnant and postpartum, making them vulnerable to poor outcomes. Known risk associations include: cardiac disease and lower quality of life (Aggelopoulou et al., 2017), cardiac disease and poorer mental health, including PTSD (Johnson et al., 2020; Vilchinsky et al., 2017), pregnancy and postpartum mental health conditions (Woody et al., 2017), as well as specific challenges for younger people and cardiac disease (Journiac et al., 2020), and mothering with chronic illness (Power et al., 2015).

Of the limited data available specifically about women with CDPP, lowered quality of life and poor mental health outcomes are noted both at the time of the pregnancy/cardiac event, as well as persisting beyond this event, in some research up to 10 years (Koutrolou-Sotiropoulou et al., 2016; Pfeffer et al., 2020; Rosman et al., 2019).

Following on from the lack of data on women's experiences and outcomes, there is a paucity of data on the specific and complex needs of women with CDPP, during their pregnancy or cardiac event and ongoing. There are currently limited tailored clinical, psychosocial or educative resources or support for survivors of CDPP or for health care professionals caring for them. Further, there are currently scant or no resources and support options co-designed by women with CDPP.

Studies on women's health, healthcare experiences and needs are essential to build patient agency, enhance the knowledge of service providers and to inform care provision. To address this need, this thesis includes qualitative in-depth interviews, an online quantitative survey, and focus groups described below.

10.3 Objective

The overarching goal of this analysis is to develop recommendations for government and non-government organisations and health professionals on strategies to improve support and resources for women who have cardiac disease in pregnancy and the first 12 months postpartum. The objective was to understand the perspectives of the participants and to undertake a preliminary exploration of options for future resource and support. The information in this chapter has been prepared as a report to the Heart Foundation.

10.4 Methods

Data on participant needs were collected through an online survey question, the results of which were then expanded upon in focus groups.

10.4.1 Needs assessment

A brief needs assessment was included as part of the anonymous online survey described in Chapter 9 and thus recruitment, ethics and population are as described in Chapter 9. Thirty women completed the need assessment question.

The needs assessment consisted of asking the participants to rate the helpfulness of various support and resource options (listed in Figure 10.1 below) as *"Not useful at all", "Somewhat useful", "Useful", "Very useful",* or *"Extremely useful".* These support and resource options were identified by participants during the qualitative interviews in Study 1. The needs assessment is presented in Appendix 4: Study 2 Online survey, Part G: Resources and support.

10.4.2 Focus groups

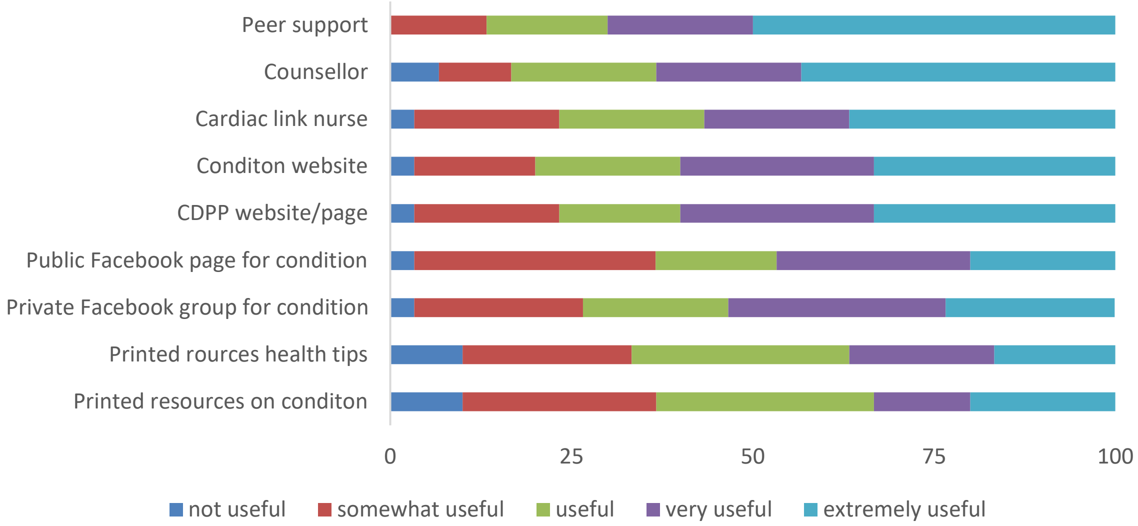
At the completion of the anonymous online survey participants were invited to submit an expression of interest to be involved in a follow-up focus group to explore the results of the needs assessment (resources and support). Twelve women responded; one was unable to attend in person and offered to provide feedback on the draft report, and two were unable to attend due to illness. Nine women participated in 2 focus groups (four in one session and five in the other session) which were conducted via Zoom online conferencing. The sessions lasted for 60 minutes and were recorded with participants' consent. The findings were summarised and provided to the participants for feedback.

10.5 Findings

10.5.1 Needs assessment

The results of the needs assessment survey indicated that peer support was rated as most helpful, with the highest number of responses *"extremely useful"* and no responses of *"not useful at all"*, see Figure 10.1.

Figure 10.1: *Needs assessment results*



10.5.2 Focus groups

The focus groups concentrated on the top three rated items (peer support, counselling and cardiac link nurse) as these were most valued and because they were potentially more complex to understand than a website that provided information on their condition. There was strong agreement amongst participants on the value, description and function of these items.

10.5.3 Peer support

Brief description

Peer Support occurs when people [with lived experience] provide knowledge, experience, and emotional, social or practical help to each other.

Informal peer support

Informal peer support includes linking with peers in social media forums (e.g., closed or open Facebook groups) and support and advocacy groups, through family and friends and incidental connections.

Participant feedback: Role and benefits

- Can join international groups which is especially useful when no local groups are available, or they have low numbers and activity, such as for the rarer conditions.
- Can access any time of day, from any location.
- Able to get feedback and information from many people.

Participant feedback: Limitations

- Large groups (typically European or USA) can have a large volume of posts which can be overwhelming.
- Feeling saturated with their health and cardiac disease, over-focusing on it.
- It can be distressing reading some people's stories, seeing images of sick babies.
- Groups may focus on the parents, not adults (e.g., in general CHD pages).
- Concerns regarding security, confidentiality of social media groups and thus hesitancy to disclose personal information online.
- Not everyone uses social media thus limiting the reach of groups.
- Groups may not cater to diversity.
- It is great to be able to join international groups but it can be difficult to learn about treatments that are not available here or that differ to local treatments, especially varying approaches to pregnancy subsequent to CDPP.

Additional researcher comments

- If health care professionals are referring women to social media groups it would be helpful to also provide some guidelines on how to interact in safe and constructive ways.
- The groups need to be appropriately moderated.
- Group moderators should have training and support, and are at risk of vicarious trauma.
- There needs to be clear guidelines for groups and how to respond to concerning posts.

Structured peer support program

Structured peer programs are facilitated by relevant and appropriate organisations or services, where peers receive training on the scope and function of their role. In structured programs there is a database of trained peers, and peer contact can be in person, online or on the phone.

Participant feedback: Role and benefits

- It gives hope that others have survived their diagnosis, have managed being a mother with their diagnosis, and are available for support.
- Speaking with others who have similar lived experience would reduce the significant isolation experienced, and help women feel safe and understood in a community of peers.
- Helps in learning to trust your body again.
- Helps re-focus and reframe the experience and one's life; helps move on from feeling like a victim.
- Normalises living, and caring for your children, going to work etc. even with cardiac impairment.
- Connecting helps to define the new normal, their new sense of self and identity, as a young woman and a mother with cardiac condition.
- Increases knowledge about existing channels of support, referral options and treatments.
- A source of realistic, practical tips for managing day-to-day.
- Can ask questions without having to wait months for their next specialist appointment (noting that the peer doesn't provide medical advice).

Participant feedback: Limitations

- Peer may not be a good match, or may not adhere to appropriate boundaries or scope of the role.

Additional researcher comments

- There was strong support for a structured peer support program.
- Peer support reduces the significant isolation, increases support, enables knowledge-sharing, helps define new self-identity and it provides re-assurance to connect with survivors and mothers with heart disease.
- Peers need to be trained and supported (e.g., on boundaries, mental health first aid, responsibilities and scope, self-care etc.)
- There is potential to model a program for CDPP on existing programs such as those in mental health and the Cancer Council.

- Ideally, the peer would be a young mother with the same diagnosis (and/or interventions such as having an ICD), but low numbers for some conditions means this may not be feasible.
- Desired peer characteristics if not a mother with same disease are, in preference order: mothers with any cardiac disease, mothers with any chronic illness, mothers with uncommon or rare medical conditions.
- In the early days after pregnancy/cardiac event you may be in shock or a trauma state, sleep deprived and overwhelmed, and may not think to seek peer support, or know how to, therefore it needs to be facilitated by health care professionals.
- It is recommended that peer connection be facilitated as early as possible after diagnosis or pregnancy, even if the woman does not access that support immediately.
- Peer support is valued not just at the time of pregnancy or cardiac event. It is sought at key events or changes including: preconception planning, pregnancy, future pregnancies, early in motherhood, children going to school, returning to work, negotiating work hours and conditions based on cardiac status if required, changes in condition, triggering events, and simply once the initial stages have passed and women have more capacity to engage.
- People without the same lived experience, or similar, often cannot understand or empathise with them. Regular mothers' groups have a different focus, and attending them can be more difficult and isolating than not attending them.
- For some participants, their offers to health professionals to be a peer support person, or simply to connect with other patients has been blocked which they described as frustrating and disappointing.
- Information on options should not be limited to any services provided by the health service/professional who is providing the referral information, and should include informal and structured peer support options.
- Peers can help fill in the gaps left when there aren't guidelines, advice or professional support, however, it would be preferable to have evidence-based guidelines and health care professional support available. For example, no woman in the focus groups was referred to allied health, including dietitians, even when given advice to have a "low sodium diet"; while a peer is not the appropriate person to say what "low sodium" is, they can share tips for cooking, or products they used that were helpful. That is, support

meeting the recommendations, not defining them, and would augment information and support given by a dietitian or other health care professional.

- May desire a short-term or longer connection.

10.5.4 Cardiac link nurse

Brief description

A cardiac link nurse would be a specialist cardiac nurse available via phone, videocall, email or forums to women across Australia who have cardiac disease in pregnancy or postpartum and beyond. Ideally each cardiac service would have a cardiac nurse to provide follow-up care, and this suggestion is in addition to that, or in place of that where no follow-up is available.

Participant feedback: Role and benefits

- Helps to fill the gap of services not having cardio-obstetric nurses, cardiac nurses that do post-discharge follow-up or for women diagnosed postpartum and may not have access to a cardio-obstetric clinic and/or obstetric physician.
- Provides information, tips for managing symptoms and restrictions due to condition.
- Avoids having to wait months to ask questions of cardiologist.
- Avoids relying on internet searches and finding misinformation and needing to be able to critique information when unwell or inexperienced in this.
- Able to provide further information on condition, other resources and services available, and referral options. For example, this might be about subspecialty areas like genetic heart disease, or how to access funding support to travel to appointments, research projects, or about support groups etc.
- This was seen to be especially helpful in the early weeks and months following CDPP when women were trying to understand situation and when information received thus far may be limited and more focused on the acute situation.
- Being available remotely (online or phone) increases access by eliminating the challenges of taking babies and young children to appointments, especially when still recovering.
- This role could also provide support for healthcare professionals seeking information and referral options, as modelled in the Cancer Council Helpline.

Participant feedback: Limitations

- It will take time to build a database of information on the specific diseases in pregnancy and postpartum, and to build database for resources.

Additional researcher comments

- Existing models exist in cancer care and can be used as models to develop a service for cardiac disease in pregnancy and postpartum.
- Need to consider the time range targeted; for example, would it be available to all women, or only for the first 5 years post CDPP?
- The participants of the focus groups expressed a strong desire for more information, as did the participants of the qualitative interviews.
- Some women had some experience with cardiac nurses working with their cardiologist or clinic, and when this extended beyond in-patient care it was highly valued. For example, knowing the cardiac nurse will be calling on an agreed schedule provided confidence and security.
- Ideally the following should be provided by the treating cardiologist and tailored to individual women and conditions, but women want a guide or checklist of what symptoms are ok, what means you should see your GP within a couple of days and what symptoms mean you need to go to the Emergency Department, as this was a new situation and they had no reference point.

10.5.5 Counselling

Brief description

The provision of mental health support as part of routine care.

Participant feedback: Role and benefits

- Mental health debriefing and support to reduce the severity and duration of mental distress and trauma.
- Better mental health helps the woman and her family, helps reduce her future cardiac and mental health risk and helps return to work if desired.

- Specific services would vary depending on the needs of the woman, including trauma therapy, adjusting to having a chronic illness that may also reduce your longevity, and grief counselling. In addition, participants sought practical solutions-focused skill development, such as problem solving, advocating for self, stress management, and anxiety management.
- Online and phone options provide flexibility and are especially helpful when have infant and/or young children at home with the woman.
- Having a counsellor check-in as routine care can help identify when and where other services may be helpful and they can provide referral information.
- If having appointment(s) with a counsellor was integrated into clinical guidelines it avoids the issues of women having to disclose distress, or even being able to self-identify the need, which can be difficult at times of distress, trauma and depression.
- It was suggested that health care professionals avoid solely relying on a screening tool like the Edinburgh Depression Scale (common screening tool in pregnancy and postpartum) to avoid the situation where women know how to answer the so that they "pass" and to foreground the personal engagement with women.

Participant feedback: Limitations

- If counselling is not integrated and delivered as routine care the same as having a cardiac test or blood test, then women may not pursue counselling support or prioritise their mental health (especially as mothers who have caring responsibilities and are time poor).
- Caring for newborn makes attending physical appointments difficult.
- Fear and stigma of seeing a counsellor (e.g., fear it makes their mental health worse, they may "unravel") may reduce women's likelihood of accessing care; this can be reduced by having counselling integrated into routine care.
- There may be cultural and language barriers to address in providing a service.
- You shouldn't have to recognise for yourself when you need help, and shouldn't have to go seeking help; you're in trauma, depleted and unwell, and have a baby to care for.

Additional researcher comments

- Strong support for mental health support.

- Counselling services should be integrated into routine care and clinical guidelines where at set time points counsellor contact is made with the woman.
- First contact to be made as early as possible.
- Solution-focused rather than long-term therapy was the priority for counsellor support after pregnancy or cardiac care. It was suggested that women can pursue long-term therapy if indicated or desired, but that is separate to counselling support discussed here, and the CDPP counsellor may be able to provide referral options for this.
- Useful if the counsellor has some understanding of cardiac disease, chronic illness, trauma and mothering concerns.
- When concerns are identified in mental health assessments they need to be acted upon; this was not always the case in women's experiences.
- Need qualified mental health professionals providing support. Support provided by other health care professionals was valued but it was recognised that mental health is a specialty area and thus appropriately qualified people were required.
- Mental health support is also important for teens and during preconception planning for women with pre-existing disease, for example, congenital heart disease.
- The transition process from paediatric to adult cardiology was felt to be sub-optimal, including as relates to mental health and women's health.

10.6 Discussion

There was support for all options in the needs assessment with *very strong* responses desiring peer support, counselling and a cardiac link nurse. These options directly address the key research findings of isolation, poor mental health and knowledge gaps.

Women described having a big learning curve when they were diagnosed or when pregnant or managing postpartum with a cardiac condition. Many women with new diagnoses have had minimal health concerns previously and largely only interacted with health professionals and services about routine reproductive health needs, so may not have developed high health literacy. Further, it is impossible to have high health literacy for conditions where there is little information available. Having to absorb complex or vague health information that may not have been communicated well when medically unwell and emotionally distressed, and while navigating early days of motherhood is exceptionally demanding. Being a mother adds another dimension and complexity, physically and mentally, as the women were trying to care for themselves while still unwell and recovering while also caring for babies and young children. More professional support is required.

Partners, family and friends may have difficulty understanding the significance or ongoing impact of women's experiences, especially as the "look the same" or are still able to perform most activities of daily living, making peer support and counselling critical. It was also noted that the partners of women with CDPP also experience a range of emotions and challenges, and need their own support. Further, they are often not able to provide the support that the women require.

Regular mother's groups or open social media pages were felt to be alienating and potentially damaging, and thus there is a need for safe spaces for women to share their concerns and discuss deeper issues.

Allied health services also need to be incorporated into routine care and referrals, e.g., exercise physiologist, physiotherapist, rehabilitation, dietitian, and occupational therapist (especially when women are instructed not to lift anything over a couple of kilograms, including the baby or other children, and no support was provided in how to manage that).

Finally, not all women have English language, reading literacy, a smart phone or use social media and options need to cater for diversity and harder to access groups (making services routine will overcome some of this).

10.7 Recommendations

10.7.1 Peer support

1. Pilot a supported peer support program, potentially modelling on existing models.
2. Provide training and support for moderators of Facebook groups.
3. Develop and provide guidelines on safely engaging with, and getting the most out of online groups.

10.7.2 Counselling

1. Integrate counselling/mental health support as part of routine care that does not require a woman to initiate.
2. First contact should occur as soon as possible, the timing of which will vary between women.
3. Initial counselling services to be support relating to acute issues and referral for on-going care as required.

10.7.3 Cardiac link nurse

1. Access to cardiac nurse support post-discharge needs to be equitable, and not dependent on which hospital or health professional the woman engaged with.
2. A pilot program could be developed that either expands the current scope of an existing localised service (e.g., one provided by a heart failure clinic in one health district), and or it could be modelled on other services such as cancer care (e.g., Leukemia Foundation or Cancer Council helpline).

10.7.4 General

1. At present there is no CDPP prevalence data in Australia; this is essential to quantify the need and plan services, therefore it is recommended that this research is undertaken as a priority.
2. Research is needed to examine the experiences and needs of diverse groups addressing social and environmental determinants of health.
3. It may be useful to target future research by timing of diagnosis (before pregnancy, during pregnancy, or postpartum), or diagnosis (or diagnostic categories if numbers are too small).
4. Women with CDPP have chronic physical illness and addressing the needs identified here will help them manage their health, and reduce the negative mental health impacts of CDPP.
5. Co-develop resource and programs with women who have had cardiac disease in pregnancy and postpartum, as they are the experts in their needs.

10.8 Conclusion

This research provides unique data on the types and features of resources and support preferred by women. This information can be used to guide further research and the development of resources and programs which ultimately improves outcomes for women.

10.9 Chapter summary

This chapter provided a summary report on the results of a brief needs assessment and subsequent focus group with women who experienced CDPP. This information is unique and has been provided to the Heart Foundation to potentially inform future pilot programs and additional support for women with CDPP.

The results from this chapter describe the clear and consistently expressed needs of women with CDPP. These results can provide the foundations and priorities for further research and the development of resources and support programs to support women and thereby improve outcomes in the short- and long-term.

The top three support options identified in the needs assessment (peer support, counselling, and cardiac link nurse) directly address the key concerns identified in the qualitative interviews and qualitative survey, that is, mental health, isolation, knowledge, and services that are responsive to their unique needs as mothers with cardiac conditions.

It is important to involve women in the co-design of future research projects and resources as the experts in their needs. The literature supports the requirements for specialised resources and support for women in pregnancy (Costa et al., 2015), postpartum (Almalik, 2017), following severe maternal morbidity (Hinton et al., 2015b) and following a cardiac event and diagnosis (Ebrahimi et al., 2021), and the findings in this chapter provides service providers, funders and researchers with valuable data.

Chapter 11: Discussion

11.1 Chapter introduction

This study used a multiphase exploratory sequential mixed methods research design to examine the experiences and needs of women with cardiac disease in pregnancy (CDPP). CDPP is an under-researched area and important findings on healthcare experiences, person-centred care (PCC) self-advocacy, mental health, quality of life, experiences of mothering and the needs of women with CDPP have been described in previous chapters, including publications and articles under review.

The three studies in this thesis have multiple points of interface in the overall study design and data have been mixed in Chapter 9 (see Chapter 3 for further detail of study design). The purpose of this chapter is to integrate data from the three studies to answer the research questions of this thesis, summarise key findings, consider the implications of the findings with a focus on three key stakeholder groups – the health care system, researchers and healthcare professionals (HCPs)– and propose recommendations for each of these stakeholder groups.

11.2 Primary findings from the study

The multiple approaches to data collection and analysis have resulted in rich data with interwoven themes. The following six overarching themes are described in this discussion: PCC, health services, mental health, quality of life, mothering with and following CDPP, and the needs of women with CDPP.

11.2.1 A lack of person-centred care for women with CDPP

Research question 1: *What are the healthcare experiences of women who have CDPP?*

The qualitative interviews in Study 1 highlighted that women’s healthcare expectations and needs were not being fully met. At times their healthcare experiences worsened their physical and mental health outcomes, reduced their trust in HCPs and harmed their ongoing relationships with HCPs and the health system in general. Chapter 4 described the study themes of:

- feeling and being dismissed,
- not receiving the information required to understand their conditions, treatment and potential long-term implications,
- lack of research, knowledge (by HCPs), clinical guidelines and continuity of care, and
- of feeling out of place within a healthcare system that did not accommodate their combined needs as a mother and as a cardiac patient.

Feeling dismissed by HCPs was the most dominant individual theme and it occurred in all settings, by all disciplines and all specialities and was iterative. Chapter 5 examined in detail the issues of feeling dismissed and having no voice. Regardless of a woman's individual attributes, knowledge and experience, self-advocating for their health and needs as a mother was complicated and difficult. Women reported that the inability to have their voices heard had negative cardiac and psychological outcomes. Chapter 6 focused on the mental health impacts of CDPP which exposed the complexity of women's psychological experiences and needs, and the lack of acknowledgement and response to those experiences and needs. This lack of mental health and social support was another dimension of feeling dismissed.

The participant responses to the new questions developed for Study 2, the quality of life (QoL) survey, reiterated the shortfalls in women's healthcare experiences and it is significant that core areas of lowered QoL and dissatisfaction were connected to the perceived level of care provided. For example, women received inadequate information, advice and support at the time of their cardiac diagnosis, or when they were advised against future pregnancies which was a deeply personal and critical issue for most women. Where women's healthcare was documented in the Mother-Generated-Index (MGI) the majority (69%) scored this as negative (8% positive, 23% neither/both).

Dismissed

The patient experience of being 'dismissed' has been documented in areas of health relevant to women with CDPP including reproductive health, cardiac disease, and rare or medically unclear diagnoses (Galick et al., 2015; Lian & Robson, 2017; Young et al., 2015). This study is consistent with earlier work that found nearly 40% of women with peripartum cardiomyopathy (PPCM) experienced symptom dismissal by HCPs and 25% were initially given inaccurate diagnoses, including “new mum anxiety” (Dekker et al., 2016). Analysis of posts on a PPCM online support group similarly reported that women felt “brushed off, dismissed and ignored”, and incorrectly diagnosed, including with anxiety (Hess & Weinland, 2012). Being dismissed increases the risk of missed or incorrect diagnoses, morbidity and potentially cardiac death, and has negative mental health impacts. All women in this study experienced delays in diagnosis or in response to deterioration of a pre-existing cardiac disease, similar to previous findings showing that it took 3 to 190 days for women with PPCM to be diagnosed (Patel et al., 2016).

Person-centred care

The experience of feeling, or being dismissed is antithetical to the principles of patient- and person-centred care. Most women in this study described a lack of patient-centred care, in which the patient participates as a respected and autonomous individual, and care is based on individual patient’s physical and emotional needs (Kitson et al., 2013). The Institute of Medicine (IOM) identified six dimensions of patient-centredness as essential to providing quality healthcare: 1) be respectful to the individuals values, preferences, and needs; 2) be coordinated and integrated; 3) provide information, communication, and education; 4) ensure physical comfort; 5) provide emotional support and 6) involve family and friends (Institute of Medicine, 2001). Reflecting on the healthcare experiences of the women in this study it is clear the goals of patient-centred care are yet to be realised, with shortfalls apparent in each of the dimensions. Person-centred care (PCC) encompasses the goals and precepts of patient-centred care and extends it to include the needs and expectations of families and communities and their role in shaping health policy and services and incorporates individuals’ personal social determinants of health; these goals were likewise not realised by or for the women in this study (World Health Organization, 2010a).

Self-advocacy

Person-centred care and self-advocacy are predicated on effective bi-directional communication which was lacking in the majority of women’s experiences. To successfully self-advocate in health, patients require three attributes: support systems, effective communication with diverse HCPs, and the ability to critique and use health information

(Hagan et al., 2017; Waddell et al., 2021). In addition to the heightened vulnerability of having a potentially life-threatening cardiac illness in pregnancy and postpartum, the women in this study had rare conditions, with little information or support available, making it difficult to self-advocate and manage their health experience. Instances where women attempted to self-advocate and navigate the health system were mostly unsuccessful. Noteworthy, the women in this research were all fluent in English language, educated and most were in professional roles, including in healthcare; and yet they all experienced difficulties in self-advocating when they had CDPP, typically on multiple occasions. If this cohort of patients had challenges with self-advocacy, and by extension with person-centred care and shared decision-making, then it is probable that others would face greater barriers, including individuals with low literacy and language skills, and low self-esteem (Hagan & Donovan, 2013; Légaré & Witteman, 2013).

Influences on self-advocacy

Influences on self-advocating in healthcare extends beyond the context of individual clinical interactions and the healthcare setting; it involves gender, knowledge and power. Knowledge required to advocate is not just about information, but it is relational. Knowledge is not neutral; what is known, by whom and what value that knowledge has is fundamentally embedded within power relationships, equity and equality (Gillberg & Jones, 2019). Failing to acknowledge women's knowledge of their bodies, symptoms and needs exists in a socio-political context of devaluing women's knowledge and lived experiences, including of illness (Cole, 2021; Werner & Malterud, 2003). Women's behaviour in the workplace, personal spaces and healthcare are influenced by these power imbalances, any previous experiences of backlash (Amanatullah & Morris, 2010; Williams & Tiedens, 2016) and a perceived self-protective strategy of being *"not the kind of woman who complains*" (Werner et al., 2004). Women self-advocating with male specialists are subverting social order on multiple dimensions; as women, as patients, as mothers, and possibly as people of perceived lower status (Bertakis et al., 2009; Chen et al., 2021).

Gender

Women are less likely to receive recommended care in related areas such as pain and reproductive health, reflecting the body of evidence that women's health concerns are less likely to be taken seriously in general, not just in cardiac care (Osborn et al., 2020; Samulowitz et al., 2018). Women with pain, including cardiac related pain, receive less intensive and less accurate treatment than men (Chen et al., 2008; Hirsh et al., 2014; Lloyd et al., 2020). Gender stereotypes and bias inform this practice and were described by the women in this study. A woman being perceived as overly emotional may retreat from self-advocating in order to maintain her self-perception and status in the eyes of HCPs, potentially at significant cost to her physical and psychological health.

Women with reproductive issues also experience being dismissed, under-diagnosed and misdiagnosed (Osborn et al., 2020). Gynaecological symptoms that are not readily diagnosable may be attributed to psychiatric disorders (Jones, 2015) and women's knowledge of their own bodies again being taken as subordinate to the authority of doctors (Lupton, 2012; Young et al., 2020). Women in this study consistently had their expertise in their body undervalued, whether it was in relation to existing disease or in describing symptoms of de novo conditions. The tendency to defer to socio-historical constructions of women and their bodies (including hysteria discourse) may be amplified in situations of medical uncertainty, and this may be relevant in the case of younger women with cardiac disease in pregnancy and postpartum (Lian & Robson, 2017; Young et al., 2019).

In all contexts, trust influences communication and self-advocacy and it is essential for safe patient care (Frey, 2011). Patient's experiential knowledge is frequently and inaccurately viewed as lacking credibility and this restricts the HCP's ability to gather clinical knowledge and establish trust and rapport (Frey, 2011; Grob et al., 2019; Nizzi, 2021). Women cannot self-advocate if HCPs don't trust them; however, mutual trust is generally lower between individuals with fewer shared characteristics, as seen with gender, ethnicity, culture and socio-economic status (Thom et al., 2011). Of note, in Australian only 15% of cardiologists and 5% of interventional cardiologists are female, and no data is available on ethnicity or other diversity characteristics (Burgess et al., 2018). Person-centred care, which supports self-advocacy, has a positive correlation with patients' trust in healthcare providers (Hong & Oh, 2020). Trust is contextual, delimited and culturally specific; a patient may have trust in one health team but not another and that trust is not transferable, but rather, it needs to be earned (Gopichandran & Chetlapalli, 2013). Further, one might have trust in the HCP but not the health care system (Dalton et al., 2021; Peters et al., 2014). Notably, trust is highest when there are three or more interactions, which is consistent with the current study, where trust and effective self-advocacy was lowest in the newest patient-healthcare professional relationships (Hong & Oh, 2020).

Health care systems

Any focus on and development of patients' ability to self-advocate needs to be mirrored by action by HCPs and health care systems and recognise the broader socio-political context. Effective self-advocacy is associated with positive outcomes however the burden of communication and person-centred care cannot rest with the party with least power, the patients (Thomas et al., 2021). Further, only focusing of self-advocacy and self-empowerment of the individual does so at the cost of ignoring systemic barriers such as under-resourcing and culture (Coddington, 2017). Encouraging patients to self-advocate with HCPs and health care systems that do not meet their self-advocacy constructively and positively risks further diminution of trust, weakening of relationships, emotional fallout, passive or active disengagement and resistance to pursue recommended treatment (Schinkel et al., 2019). Whether it is in an acute or chronic health situation, having to constantly work hard to convince others of your credibility is exhausting (Werner & Malterud, 2003), and I would suggest unreasonable for patients to repeatedly have to. Ensuring healthcare is person-centred is not simply about trying to moderate the actions and attitudes of HCPs either. It is neither feasible or fair to solely rely on the professionalism, empathy and excellence of individual HCPs to provide PCC *despite* the system within which they work. Rather, patients and HCPs need and deserve a healthcare system that carries the burden of implementing PCC and enables HCPs to deliver excellent care.

The deficits in health care and the vulnerability and barriers experienced by women with CDPP in this study are significant and complex. These deficits have led to delayed diagnosis and treatment and psychological distress. They occurred in the context of study participants who has excellent communication skills, and yet this was still their experience of healthcare with

CDPP. Self-advocating as a woman who has experienced, potentially lifelong, personal and systemic racism, who is differently abled and been unable to access appropriate care, who is of a different socio-economic status, religion or sexuality to the majority of HCPs would be exponentially more difficult (Crenshaw, 1991).

Positive experiences

It is important to note that while most of the stories the women shared were of negative healthcare experiences, this does not imply that all of their healthcare experiences were negative. Some positive experiences were described, particularly those highlighting the value of sharing information and respectful communication. In addition, it is likely that all the actors in health care experience some degree of struggle, as described by health activist Sue Robins:

> *It is the lack of humanity that ails health care. There is a lack of humanity for patients, families, staff, clinicians, physicians and administrators. Every single person who touches health care, from the attendant in the parkade to the ICU patient, is suffering right now in health care settings because of a basic lack of humanity. We are all in this mess together.* (Robins, 2019)

A poignant example of this was the GP who had dismissed and misattributed a women's cardiac symptoms for two years as being due to excess weight; when the woman was eventually diagnosed with hypertrophic cardiomyopathy the GP attended her in hospital to apologise and was visibly remorseful and upset.

The issues the women in this study described of feeling unheard, unsupported and under-resourced also applies to HCPs as they navigate the healthcare system, and any effort to work to the betterment of patient experiences and health outcomes needs to acknowledge this.

11.2.2 Health services not meeting the needs and expectations of women with CDPP

Research question 1: *What are the healthcare experiences of women who have CDPP?*

Women in this study variously felt that they were viewed as 'all baby' or 'all heart' but never as a whole person or mother, and they typically felt 'out-of-place' in whatever service they were attending. They described that their health care needs both within and beyond the hospital setting were not recognised or responded to. They felt that they were seen as a diagnosis and not a person and did not feel included in decision-making. The needs of women with CDPP were not met at the individual clinician, local health service and policy level. Additional issues affecting healthcare relate to research, education, service delivery and design, all of which are underpinned by funding priorities and allocation.

Optimal clinical outcomes, person-centred care and self-advocacy are dependent on accurate information, which in turn is dependent on research, however, CDPP is under-researched in Australia and globally. International prevalence estimates are 1% to 4%, with evidence of increasing prevalence due to delayed childbearing in middle and high-income countries, growing rates of cardio-metabolic risk factors (Regitz-Zagrosek et al., 2018) and increasing numbers of congenital heart disease survivors having children (McClure et al., 2011). Current estimates of prevalance and mortality, and the scale and nature of morbidity, are likely to under-ascertain the disease burden (England et al., 2020; Malhamé et al., 2020; Masoomi et al., 2018; Sliwa et al., 2015). In particular, prevalence, mortality and morbidity data inconsistently include women diagnosed in the late and very late postpartum periods (Vijayaraghavan et al., 2014). Despite this under-estimation, cardiovascular disease has been a leading medical cause of maternal death in Australia for the past five decades, responsible for 14.36% of all maternal deaths between 2009 and 2018 (Australian Institute of Health and Welfare, 2019b). CDPP is associated with serious maternal morbidity across physical, psychosocial and functional domains as found in this research. An estimated one in four women with cardiac disease during pregnancy requires hospitalisation (Roos-Hesselink et al., 2013) and for each maternal cardiac death nearly eight women have severe maternal morbidity (Huisman et al., 2013).

Based on a prevalence of 1% to 4%, there are 1.3 to 5.2 million women affected annually by CDPP globally, of which it is estimated between 3,150 and 12,600 are Australian (Australian Institute of Health and Welfare, 2020a). The lack of epidemiological, clinical, quality of life and lived experience research of this considerable cohort of women who have significant mortality and morbidity *is in and of itself, a reason for further inquiry*.

Research and guidelines

The lack of Australian research into CDPP is highlighted against significant amounts of research into other critical areas such as gestational hypertension and pre-eclampsia which have similar prevalence rates (3.0 – 4.0% and 3.0 - 3.3% respectively) (Australian Institute of Health and Welfare, 2021a; Thornton, Dahlen, et al., 2013; Thornton et al., 2016); and I wish to note that this comparison is made for contextual understanding and not to create or suggest a competition between diseases.

The women in this study perceived a lack of research-informed clinical guidelines and clinical education in CDPP and expressed frustration, disappointment and at times, concerns about their safety in the care provided. They understood that their conditions may be rare in pregnancy and postpartum but also that this perception may be inaccurate, in part due to research and treatment involving women. Women are under-represented in cardiac research in general (Doull et al., 2010; Jin et al., 2020; Lam et al., 2019; Norris et al., 2020) and research specifically on CDPP is limited. Women with cardiac conditions are under-diagnosed, under-treated and less likely to have interventions and treatment adherent to clinical guidelines (Arora et al., 2015; Bachelet et al., 2021; Johnson et al., 2018). As seen in this research, women are less likely to be referred to cardiac rehabilitation even though attendance is associated with a greater reduction in mortality for women than for men (Colbert et al., 2015; Colella et al., 2015). Consequently, women with cardiac disease have worse morbidity and mortality outcomes (Alabas et al., 2017; Butters et al., 2021).

Healthcare professionals’ knowledge

In addition to a lack of disease-specific knowledge due to limited research, this study identified more basic shortfalls in clinical care regarding general knowledge and clinical assessment and reasoning skills, including being able to perform and interpret common assessments such as electrocardiograms (ECGs). HCPs without adequate education and training in CDPP are compromised in their ability to provide excellent clinical care or person-centred care. HCPs are often working across specialty areas; when in the absence of specialist units, a woman with CDPP may be admitted to a cardiology, maternity, or a general medical ward. HCPs may have limited knowledge and experience in caring for women with CDPP and may feel less confident or competent in these situations.

Health care system

Excellent clinical outcomes are dependent on health systems that support patients, HCPs and non-clinical staff (Institute of Medicine, 2001; Nyhof et al., 2020). Health services and systems more broadly have responsibilities to patients and staff; ensuring adequate staffing and resources, allocating funding for research, providing appropriate staff education and support, and developing guidelines to facilitate best practice are ways to meet these responsibilities. Tailored health management that acknowledges patient experience, especially for long-standing and complex conditions, would improve patient outcomes (Pickard & Rogers, 2012). Positive HCP outcomes include a reduction in the risk of burn-out and physical and psychological illness, and improved job satisfaction. This results in improved staff retention for health services, and better clinical outcomes (Eadie & Sheridan, 2017).

Continuity of care

An additional health system characteristic required for excellent clinical outcomes is the integration of continuity of care, which is quality care over time in which a series of discrete health care events is experienced as coherent and interconnected, and compatible with the patients' health needs and preferences (Deeny et al., 2017). Data show that continuity of care and care coordination is highly valued and is central to PCC; it facilitates trust through ongoing relationships with HCPs and reduces emergency department (ED) presentations, hospitalisations and overall health expenditure (Deeny et al., 2017; World Health Organization, 2018).

Care coordination

Women with CDPP often have long-term complex conditions and care requirements that need the involvement and coordination of care from multiple HCPs across different specialities and disciplines. The results of this study reflect those by Hinton and they highlight gaps in coordination and continuity of care, leading to fragmented and inadequate care for women who presented with CDPP (Hinton et al., 2014). At the time of writing cardio-obstetric clinics remain a rarity in Australia, not all hospitals offer both maternity and cardiac services or the expertise of an obstetric physician. This lack of co-located obstetric and cardiac services may jeopardise communication and co-ordination between teams (Knight et al., 2016). Research supports the need for specialised resources and support for women in pregnancy (Costa et al., 2015), postpartum (Almalik, 2017), following severe maternal morbidity (Hinton et al., 2015b) and following a cardiac event and diagnosis (Ebrahimi et al., 2021). Further, the women in this study experienced little involvement of anaesthetics services in caesarean section care planning and little or no allied health involvement at any stage. Even when women in this study were assertive and proactive, their attempts to coordinate their own care and act as liaison between HCPs of different disciplines failed.

Postpartum care

Finally, while cardio-obstetric units or clinics are ideal, their scope of services is not extended to women diagnosed in the postpartum period (following discharge from hospital after their birth event). Postpartum deaths accounts for more than 50% of combined CDPP deaths (Lameijer et al., 2020), yet this figure is likely higher as data is often limited to 7 to 42 days postpartum-(Sliwa & Anthony, 2016), and while overall maternal death have decreased, post-partum and late maternal deaths have not declined in the past decade (Sliwa & Anthony, 2016). Further, women with CDPP (acute and ongoing) may have more complex cardiac and QoL issues than is usually seen in general cardiac clinics including issues relating to mothering infants and small children (Rosman et al., 2019). A parenting role may negatively affect engagement with medical recommendations, such as the ability to follow recommended diets, exercise, rehabilitation, attendance at appointments and taking medication as prescribed. Hence these considerations need to be factored into fit-for-purpose service design (Rosman et al., 2019). Women in this study described barriers to attending ongoing cardiac appointments due to lack of physical access and parking, cost of consultations, long waiting room wait times and the challenges at having infants and young children with them when they were unable to access childcare. Enhanced education, research and continuity of care, especially in general practice and community nursing and midwifery services, may address some of these postpartum outcomes.

11.2.3 Reduced mental health during and following CDPP

Research question 2: *What is the impact of having CDPP on women's mental health?*

Analysis of the interviews in Study 1 produced three major themes;

- index events and their emotional and psychological impact,
- self-perception, identity and worthiness, and
- isolation and connection.

The themes were consistent across the interviews despite the women being diverse in age, cardiac diagnosis and cardiac health status, parity and timing of diagnosis. The narrative connecting the women despite temporal and clinical differences was one of distress, grief, biographical disruption, loss of identity, isolation, a necessitated re-imagining of their lives, and the process of multi-layered healing. All while still recovering from pregnancy, birth, a cardiac illness, and with an infant to care for.

In Study 2 clinically significant levels of anxiety and depression were scored in both the Depression, Anxiety and Stress Scales-21 (DASS-21) and Cardiac Anxiety Questionnaire (CAQ) instruments. DASS-21 results indicated higher prevalence of depression, anxiety and stress amongst participants compared Australian norms, with mean scores of 4.29 vs 2.57 for depression, 3.41 vs 1.74 for anxiety and 6.27 vs 3.99 for stress and total DASS-21 of 13.98 vs 8.30 (Hawthorne et al., 2006). Combined scores for moderate, severe or extremely severe rating were 24% for depression, 22% for anxiety and 20% for stress indicating important findings of mental distress. There are no validated clinical cut-off scores for the CAQ however the scores for 45.2% of all participants indicated at least moderate cardiac-specific anxiety.

This research demonstrated that women with CDPP often have complex and distressing experiences that affect their sense of identity and mental health beyond their pregnancy or first year postpartum. Many of the experiences described by the participants are similar to those described in the literature on the lived experiences, mental health, self-identity and recovery of other populations such as cardiac, maternal, rare disease, chronic illness, trauma, birth trauma, severe maternal mortality and women with high-risk pregnancies (Dekker et al., 2016; Elmir et al., 2010; Lian & Robson, 2017; Liang et al., 2014; Shockley, 2012). The women in this study were part of most, or all, of those populations making them uniquely exposed to multiple and compounded risks.

The results of Study 1 are consistent with previous findings that women diagnosed with CDPP feel terrified, devastated, have a sense of doom, and feel a loss of trust in the health system after having symptoms dismissed or misinterpreted by HCPs as psychiatric symptoms (de Wolff et al., 2018; Dekker et al., 2016). Many of the women in this research had been acutely unwell, some with life-threatening episodes, they had intense and or prolonged pain and significant decreases in functional capacity yet most described the mental health effects as having the greatest impact on them. Further, the lack of mental health and social support was reported to be at least as pronounced and harmful as the sparse amount of cardio-obstetric clinical research informing evidence-based practice.

CDPP and mental illness

While the literature is limited, it demonstrates that CDPP is associated with significant mental illness. A recent study found 26 of 40 participants had a major mental health disorder diagnosed after experiencing peripartum cardiomyopathy (PPCM) and that compared to postpartum women without PPCM, the prevalence of major depressive disorders was 4-fold, post-traumatic stress disorder (PTSD) was 14-fold, and panic disorder was 6-fold (Pfeffer et al., 2020). Women of reproductive age with heart disease report feeling stress, difficulty taking control and making decisions, a lack of autonomy, and the need for social support (Dawson et al., 2018). Women with pregnancy-related spontaneous coronary artery dissection (PSCAD) are reported to have almost twice the scores for anxiety and depression compared with men and non-pregnant women who had a spontaneous coronary artery dissection (SCAD) (Liang et al., 2014). Further, a systematic review estimated the overall prevalence of perinatal depression to be 11.9% (Woody et al., 2017), and recent research found significantly higher rates of emotional neglect and physical, emotional and sexual abuse among adults with congenital heart disease (CHD) compared to those without CHD. This highlights a multitude of risks and factors that need to be considered when caring for women with CHD and CDPP in general (Proskynitopoulos et al., 2021).

The findings on mental health and cardiac disease in this thesis are disappointingly predictable and are evidence of a persistent lack of integrated mental health and social support for women with CDPP despite evidence of its need (Liang et al., 2014; Woody et al., 2017). In particular, younger women appear to be more exposed to the risk of reduced mental health (Liang et al., 2014) and some cardiac conditions, including those experienced by this population, have higher rates of associated mental health issues (Johnson et al., 2020; Liang et al., 2014). The bi-directionality of mental health and cardiac disease means anxiety, depression and PTSD, as well as other mental health conditions, are associated with lower attendance at medical follow-up visits, poorer cardiac outcomes, more recurrent cardiac events and higher mortality (O'Neil et al., 2021; Rosman et al., 2019; Smaardijk et al., 2019).

Suicide

Cardiac disease and suicide are leading causes of maternal mortality in middle- and high-income countries (Australian Institute of Health and Welfare, 2020b; Knight et al., 2019; Lommerse et al., 2019). These figures are likely to underestimate the prevalence due to reporting differences and that most jurisdictions only include data up to 42 days postpartum (Knight et al., 2019; Lommerse et al., 2019). A 15-year population study in Canada (Grigoriadis et al., 2017) is consistent with an earlier Australian study (Thornton, Schmied, et al., 2013) that found the peak in suicide occurring between 9 and 12 months postpartum. Critically, compared to matched living women, perinatal women who died by suicide had a similar pattern of use of non-mental health primary care and obstetric care to women who do not suicide before the index date, reflecting a missed opportunity to intervene, support, treat, and prevent this loss of life (Grigoriadis et al., 2017).

Risks factors for maternal suicide include being Aboriginal, a history of mental illness, lack of recognition of mental health, medical illness, poor inter-disciplinary communication and lack of continuity of care (Australian Institute of Health and Welfare, 2020b; PMMRC, 2017). The prevalence of self-harm, suicidality and anxiety are increasing in young women (Stefanac et al., 2019) and when they seek support for self-harm and suicidal ideation young women report feeling patronised and dismissed, and that ED experiences increase their risk of future self-harm (Byrne et al., 2021). Thus, some of the risks for maternal suicide are increasing without a concurrent increase in effective intervention prior to pregnancy or once a woman is pregnant or postpartum. Further, the experiences of young women being dismissed, the lack of recognition and lack of continuity of care mirror the experiences of the women in this study when needing mental health, cardiac and obstetric care, and this repetition compounds their risk for poor mental health outcomes.

Dismissed

As previously discussed, the experience of being dismissed was associated with delayed cardiac and mental health diagnoses, and not receiving information when it was available. These experiences reduced women's agency and amplified the sense of low internal locus of control, as explored in Chapter 5. This study was comparable to earlier research which reported that when women with maternal morbidity were dismissed and not listened to, or when they didn't fully understand the situation, they felt disempowered and a had a lack of health locus of control that persisted months after their health care experience (Meaney et al., 2016; Redshaw & Hockley, 2010). Consistent with previous studies, for women in this study feeling confident in their sense of self was most challenged when they were in acute medical situations and when they experienced medical gas lighting; the dismissal and invalidation of their sense of self and lived experience (Byrne et al., 2017; Peeler et al., 2018).

Autonomy

When unwell, women may experience difficulty in making decisions and in having others making decisions for them (de Wolff et al., 2018; Hess & Weinland, 2012; Hess et al., 2010). Most women in this study were advised to cease breastfeeding and or to have no further pregnancies. They described having no bodily autonomy and that this advice was most commonly issued as a directive, and not introduced as a discussion with the opportunity to discuss their desires and values (de Wolff et al., 2018; Dekker et al., 2016). This loss of autonomy as well as previous subfertility and pregnancy loss, and the abrupt change to expected family size is disempowering and complicates grief. Perinatal loss, infertility and medical reasons to not have children are ambiguous losses, which are characterised by the simultaneous physical absence of, but psychological presence of the foetus or infant (Boss, 2007; Boss & Couden, 2002; Lang et al., 2011). Ambiguous loss, for the children hoped for but never conceived, is associated with feeling frozen in grief, lack of support, and lack of recognition and rituals of grief. In the context of surviving a "concurring crisis" (Doka, 1999) of a complicated pregnancy or postpartum cardiac event this ambiguous and invisible loss may not be recognised by others including healthcare professionals and women may feel unable to talk about it (Boss, 1999). The mental health impact of ambiguous loss may thus be complicated by disenfranchised grief in which a person experiences a significant loss and the resultant grief "is not openly acknowledged, socially validated, or publicly mourned" (Doka, 2008 p224) which exacerbates their suffering. This psychological intricacy and layering was not explored or supported for the women in this study.

Self-identity

Physical and mental illness, loss, and embarking on motherhood, especially for the first-time, provoke a changing sense of self and of self-identity (Asbring, 2001; Charmaz, 1983; Doka, 2019; Wisdom et al., 2008). Motherhood involves a fracturing of a woman's identity to allow space for a new identity in her new life (Laney et al., 2015). This rupturing and reformation is a multidimensional process comprising the stages of triggering event (becoming a mother), loss of self, and redefining the new self; the women in this study repeated this process with the trigger event of CDPP. The women's descriptions of cardiac and mental illness, pregnancy, birth and motherhood, identity and recovery were congruous with Wisdom's analysis relating to mental illness (Wisdom et al., 2008). In this, participants described a loss of identity/self, the duality of being ill and well (of having cardiac disease and being a mother), perceptions of normality (the 'new norm'), and their specific concerns about the impact on parenting, and recovery and reconciliation.

Pregnancy, birth, the postpartum period, breastfeeding and illness are fundamentally embodied experiences. The body is our access to perceiving and interacting with the world and is integral to identity and sense of self (Merleau-Ponty & Landes, 2012). Biographical disruption is a disruption or disturbance of one's embodied perception and experience of the world (Bury, 1982). A body changed by pregnancy and motherhood, and which is also now an unreliable body due to cardiac disease, complicates and unsettles existing identity and sense of self, and changes the way one interacts with the world. Illness (cardiac, mental, maternal) disrupts that which was taken for granted such as being able to pick up your baby, work, or play in your team sport, and causes a "*fundamental re-thinking of a person's biography and* *self-concept*" (Bury, 1982 p169). Moreover, chronic illness involves a continued adaptation, an ongoing struggle to *"maintain control over the defining images of self and over one's life"* (Charmaz, 1991 p5). As their cardiac status, mental health and experiences of mothering change, women with CDPP have an enduring experience of re-defining self and identity, managing their illnesses and grief, and accepting and making sense of their lived experiences; managing their cardiac condition is only one aspect of this evolving and multi-layered process.

Self-identity is formed through reflection of our peers, and verified or rejected through our interactions with others, including healthcare professionals, through whom we internalise a felt sense of what it means to be ourselves, incorporating values and judgments that have been perceived (Doka, 2019; Stets & Serpe, 2013). Mothers build their identity in part through engaging with peers in antenatal and mother's groups that many of the participants in this study were unable to join. People with illness compare themselves to others they know with the condition, or the knowledge they already had of the condition. Women change their self-perception post cardiac event, both positively and in the sense of losing one's prior self (Shockley, 2012). Most women in this study had no, or few, peers of other mothers with similar conditions with whom to compare and mirror. Redefining self-identity was both complex and integral to healing for participants who had multiple triggers for biographical disruption and loss of self. Having cardiac disease amplifies the physical, emotional and sociological vulnerability that women experience perinatally and in the postpartum period (Dekker et al., 2016).

Isolation

The women in this study largely traversed these experiences and phases without connection with peers and this sense of isolation increased their suffering. When they were able to connect and 'see themselves in the stories of others', often through Facebook support groups, they mostly felt validated and re-assured that others had similar symptoms and experiences, and that they were simply still alive. The telling of their stories is more than a retelling of events, rather it can be reparative and facilitate the conception of their new self (Kostick et al., 2019). The women found several ways to control or at least own their own narrative. They did this by not staying 'immersed in their illness', seeking improved communication, providing others support, advocacy, and involvement in research (Green, 2004).

Complex recovery

Regaining a sense of control and autonomy was an important step in recovery and this was underpinned by their sense of self. Recovery here is not taken as returning to one's premorbid condition or to cure, rather it is about recalibrating and finding equilibrium; having a chronic illness means having to adjust and re-adjust, developing new ways to manage for life (Charmaz, 1991). Recovery for the women was complex and non-linear. It was comprised of a partial return to their previous health and life and a partial creation of a new identity and life, now with a chronic health condition and a baby. This research is consistent with previous research that found that women with PPCM struggled to recover psychologically, that little or no professional mental health support was provided and that women felt invisible and isolated during recovery (de Wolff et al., 2018). Of note, Koutrolou-Sotiropoulou, Lima, and Stergiopoulos found that more than half of women with PPCM did not return to premorbid levels of emotional health after one year despite 68% having recovered cardiac function, highlighting the persistent emotional toll of CDPP on young mothers (Koutrolou-Sotiropoulou et al., 2016). The average time since their experience of CDPP for the participants of both the interviews and the survey was five years and their mental health subsequent to their experiences remained a priority issue for them.

In the results of Study 2 for DASS-21 and CAQ participants were twice as likely to score at least moderate anxiety on the CAQ (45%) compared to the DASS-21 (22%) which may reflect sensitivity and or specificity of heart-related anxiety compared to general anxiety. The total and domain scores for the CAQ were comparable to Rosman's study of women with peripartum cardiomyopathy (Rosman et al., 2019), and notably higher than studies on cardiac patients in general (Christoph et al., 2014; Eifert et al., 2000) and people presenting to the emergency department with non-cardiac chest pain (Mourad et al., 2016). The scores were decidedly higher than norms for women of a similar age range who didn't have cardiac disease (Fischer et al., 2011). The CAQ subscale of avoidance may indicate heart-related anxiety, or it may reflect appropriate self-management and following medical advice, and this is worth further examination. Questions relating to interactions with HCPs and access to healthcare are also noteworthy, reflecting anxiety about their health and management by health professionals. Importantly, cardiac anxiety, depression and other mental health conditions are associated with increased risk for further cardiac events and mortality (van Beek et al., 2016), in particular, in women (O'Neil et al., 2021). These responses suggest a need for improved information and knowledge sharing, skill development and the provision of specialist counselling and psychiatric support (van Beek et al., 2014).

11.2.4 The impact on mothering with and following CDPP

Research question 3: *What is the impact of having CDPP on women's experience of mothering?*

Thematic analysis of the interviews in Study 1 generated the themes of:

- women's self-identity as a mother first,
- issues that were a big deal,
- motherhood not being as they'd due to CDPP, and
- interrupted connections (with their babies).

The women's self-identity, physical recovery and world-view was as a mother first. Despite feeling symptomatic of their cardiac condition (both before and after diagnosis), women prioritised their role as a mother and the needs of their children, including in ways which may have negatively affected their cardiac health. Issues surrounding fertility and breastfeeding, and possible genetic and cardiac testing of their children were paramount to the women, and they struggled with the lack of acknowledgement and care in discussions on these matters. Being separated from her infant and older children was distressing and relinquishing care was emotionally complex. Navigating physical restrictions impacted their ability to mother, and live in the manner they imagined. In study 2 the Primary Mother-Generated Index (MGI) score was 4.8 out of 10 indicating an overall negative experience within the month before the survey. Overall, 56.6% of responses rated areas of life as a mother with CDPP as negative, 17.9% as positive and 25.5% as both/neither. The MGI revealed additional domains of importance including relationships, longer term outlook, feelings about self and career and financial issues. The newly developed questions in Study 2 identified that the majority of women were advised to avoid future pregnancies which was distressing, with most (88.9%) scoring receiving this advice as "upsetting" through to "devastating". Another dimension to women's distress was having a history of subfertility, miscarriage and stillbirth, and now having frozen embryos in IVF clinics that they would need to discard, and this was neither explored or acknowledged. Reflecting healthcare experiences previously described, only 10% of women were offered or had counselling suggested about the advice to have no future pregnancies, despite it being a distressing aspect of their CDPP experience. Women's concerns about longevity were typically expressed in relation to being able to raise their children, and they were also concerned about their children developing a cardiac condition and had to navigate complex decisions about testing and telling their children.

Novel findings

The study findings presented in Chapter 8 of this thesis are to the best of my knowledge the first to focus on women's experiences and QoL as mothers with a range of cardiac diseases diagnosed before or during pregnancy, or in the first 12 months postpartum. Additionally, I believe that Study 2 is the first to adapt the MGI to be specific for mothering with a chronic illness and to extend the evaluation period beyond 12 months postpartum. Finally, another unique feature of this research was the inclusion of new QoL questions relating to the importance and impact of decisions regarding the women's fertility and mothering.

On being a mother

The dominant theme in both Study 1 and the MGI in Study 2 was the primacy of motherhood and mothering in the women's view of themselves, their needs and priorities. This was illustrated in the weighting of the MGI responses and in the strength of interview data, and was reiterated in the other QoL questions in Study 2. Women's identity and expectations of themselves as mothers has been explored in the literature and is an evolving field of inquiry (Balaji et al., 2007; Lawler et al., 2015; Luthar & Ciciolla, 2015; Power et al., 2015). Some studies have examined reproductive choices and motherhood for women with an acute or chronic illness, severe maternal morbidity or near-miss (de Wolff et al., 2018; Dorgan et al., 2013; McCoyd et al., 2018; Power et al., 2015; Vallido et al., 2010). However, with the increasing prevalence of chronic illness and CDPP in particular (Lima et al., 2017), this work is essential to improve outcomes for women and their children, and to maximise health care efficiency (Admon et al., 2018; Hinton et al., 2015b).

Family planning

A small amount of research has focused on issues of risk and decision-making in family planning (Cauldwell et al., 2017; Ngu et al., 2014a, 2014b), contraceptive choices and use, and unplanned pregnancies for women with cardiac disease (Cauldwell et al., 2017; Holton et al., 2018; Kaemmerer et al., 2012). Women with cardiac disease have similar desires to have families as women without cardiac disease; however, they may underestimate risks. HCPs may also underestimate women's desire for children and not provide adequate family planning education and preconception counselling. The benefits and risks of different contraception choices may not have a robust evidence-base due to low numbers and little research. Australian research found that women with chronic non-communicable diseases (NCD) were significantly more likely than women without an NCD to have ever been pregnant, have an unintended pregnancy and a have termination of pregnancy (Holton et al., 2018). An earlier review of pregnancy termination performed for maternal indications in an Australian tertiary obstetric referral hospital found 12.5% of cases were due to a cardiac reason (Barrett et al., 2011). In all cases the cardiac diagnosis was known before conception and contraceptive rates in this at-risk group were poor, warranting attention. Providing preconception planning and advice to women with cardiac disease is affected by the limited evidence-base to inform guidelines and advice, however it remains important to address in a person-centred approach, and could be modelled on existing templates such as the Modified Reproductive Life Plan for women with chronic disease (Mittal et al., 2014).

Impacts of being advised to have no future pregnancies

Most women in this research had been advised to have no further pregnancies and this was difficult and distressing advice. The manner in which it was communicated compounded the women's suffering. The women scored low HRQoL and their inability to have more children may be a contributing factor with the research finding QoL is significantly associated with greater reproductive concerns (Wenzel et al., 2005). Further, the women in this research reported anxiety, depression and poor mental health that persisted many years after their CDPP, and their fertility may be a contributing factor. This is congruent with research on women who had a diagnosis of cancer that disease and treatment impacts on childbearing were a significant contributor to distress and depressive symptoms, as late as ten years after their diagnosis (Canada & Schover, 2012; Gorman et al., 2010; Logan et al., 2019). Communicating advice to have no further pregnancies is critical to person-centred care and women's mental health and QoL, and HCPs could look to guidelines used in fertility clinics to model practice (Dancet et al., 2011).

Breastfeeding

Some women were advised to cease breastfeeding and this can be devastating (Dekker et al., 2016). No women were offered emotional support, and practical support such as borrowing a breast pump was only provided when the women asked for it. Women can have mixed experiences and feelings about breastfeeding, but having choice is imperative and when this autonomy was removed it compounded the anguish and grief women experienced. Other women had difficulty breastfeeding as a result of chest surgery due to their cardiac condition. Clinical or biomedical language in providing advice to women can be alienating and counter to women's embodied experiences of breastfeeding (Burns et al., 2010). For the women in this study breastfeeding was more than nourishing their infant, it was about connection, which is consistent with the literature on women's descriptions of their breastfeeding experience being one of closeness with their infant (Burns et al., 2010).

Women may feel guilty for having to cease breastfeeding, with this advice further evidence (on top of their cardiac issues) of their bodies no longer being reliable. Their response to their cardiac condition, birth, and advice to avoid future pregnancies was intensified by their experiences of breastfeeding and stopping breastfeeding; this was not explored in detail in this research and warrants deeper investigations.

Birth experiences

The physical effects of CDPP can affect how and when a woman gives birth, her recovery from birth, the health of her baby and early connection with and care of her infant. Mothers with serious maternal morbidity or maternal near-miss events and initial separation from their newborn, experience distress, delayed or impaired infant bonding, challenges establishing breastfeeding, and require additional support (Hinton et al., 2015a, 2015b; McCoyd et al., 2018). Traumatic birth experiences also impact on a woman's experience of motherhood and her initial relationship with her baby, with women reporting lost bonding time, feelings of failure and the emotional impact of ‘relinquishing care of the infant’ (de Wolff et al., 2018; Dekker et al., 2016; Elmir et al., 2010). A diagnosis of cardiac disease in pregnancy or postpartum may be completely unexpected. Being unwell with cardiac disease impacts women’s ability to care for their newborn or return to normal activities of daily life, and leads to additional distress (de Wolff et al., 2018; Dekker et al., 2016). As experienced by the women in this study, mothers struggle to surrender care even when acutely unwell, and the importance of their role as mother is not always fully appreciated or facilitated by HCPs (Power et al., 2015). Further, women may experience difficulty making decisions and having others making decisions for them, as described in this thesis (de Wolff et al., 2018; Hess & Weinland, 2012; Hess et al., 2010).

Mothers not prioritising their own health

Lastly, the women in this research typically prioritised their children over their own health, often with negative outcomes. In addition to this, not being able to attend medical appointments due to lack of childcare and managing the physical restrictions of their conditions, women face challenges managing their acute and ongoing chronic health condition while simultaneously mothering their infant and young children (de Wolff et al., 2018; Power et al., 2015; Rosman et al., 2019; White et al., 2009).

11.2.5 Reduced quality of life subsequent to CDPP

Research question 4: *What is the impact of having CDPP on women’s quality of life?*

Quality of life was assessed in Study 2 using the WHOQoL-Bref, Kansas City Cardiomyopathy Questionnaire (KCCQ) and newly developed questions to assess general and patient-reported health-related quality of life (HRQoL). QoL data related to mothering with a cardiac condition are discussed in 11.2.4 Mothering. This study found that the overall QoL in the WHOQoL-Bref was comparable to Australian norms but was notably lower for health satisfaction (mean 51.7 vs 72), physical health (mean 55.2 vs 80.0), psychological health (mean 64.9 vs 72.6) and social relationships (mean 63.0 vs 72.2) for women with CDPP (Murphy et al., 2000). The WHOQoL-Bref domain scores were also markedly lower than norms for similarly aged females, in particular for the domains of physical health, (55.2 vs 80.3), psychological (64.9 vs 73.6) and social relationship (63.0 vs 74.8) (Hawthorne et al., 2006).

Health-related quality of life

The KCCQ health-related QoL results highlighted important issues relating to information, communication, support, self-management, outlook, mental health, employment and financial concerns. Key findings included the majority of women feeling they were provided with inadequate and/or unclear information about their diagnosis, and in particular 18.6% received no information or advice regarding their diagnosis. Access to appropriate healthcare is essential for QoL, and in addition to concerns about healthcare experiences discussed above, Study 2 found that 41% of women had missed at least one medical appointment due to difficulty arranging childcare and when medical appointments were not free of charge, one-quarter of women had missed at least one appointment due to cost. Financial security and employment are also determinants of QoL and more than half of women (60%) had stopped or reduced employment due to CDPP.

Questions on the importance and impact of pregnancy decisions, described in 11.2.4 Mothering, is a unique feature of this research. Additionally, women's CDPP and associated issues affected their intimate relationships with nearly one-third (31%) of sexually active women worried that having sex would harm or be unsafe for their heart. Women surveyed were concerned about surviving long enough to raise their children and about their children developing a cardiac condition. Women reported they were discouraged because of their condition and that their ability to enjoy life was restricted. In Study 1 women described restrictions in mothering, employment, social engagement, access to services and healthcare that did not fully meet their needs; all important aspects of QoL.

There are numerous definitions of both QoL and HRQOL with no consensus as to the most accurate or appropriate one to use (Thompson et al., 2016). A commonly used definition of QoL is provided by the WHO:

> *…an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social*

> *relationships, and their relationship to salient features of their environment.* (WHOQOL Group, 1994 p.43).

This definition has several strengths, including that it is a broad concept of QoL and health that is not limited to biomedical aspects, and it can be used in different cultures, ages and health conditions (Bakas et al., 2012). QoL research is essential to understand individuals' experiences and needs, and the assessment, interpretation and response to findings needs to be nuanced. QoL is subjective and is influenced by the mental health, personality traits, preferences, value system and experiences of individuals (Chmaj-Wierzchowska et al., 2022). It is also influenced by timing, for example, patients in the early post-operative period report feeling they've had a rebirth, grateful and optimistic, which may lead to overestimation of their quality of life (Åberg, 2020). This may apply to the women in this study; surviving the acute cardiac event or challenging pregnancy and birth, initial responses may be gratitude and relief and a perspective through 'rose-tinted glasses', however, after time has passed their views may be more objective or analytical. The average time since CDPP in this study was 5 years; the lack of marked improvement in QoL over time may be due to the chronicity of their health condition, but also due to this re-evaluation and reflection once clinically stable.

Patients and HCPs have differing perceptions on QoL (Thompson et al., 2016; Wiering et al., 2017a), and studies measuring changes in clinical outcomes and functional capacity report incommensurate changes to patient reported QoL and wide variability of what individuals view as important (Carr et al., 2001; Hallan et al., 1999; Wiering et al., 2017a). Another consideration is the concept of cause and effect; a biomedical approach posits health is a key determinant of quality of life, but one's quality of life is also a key determinant of health (Barofsky, 2011; Thompson et al., 2016). Revisiting and adapting the WHO definition of QoL above, it is possible to see how both of these positions can be true, and in the case of a young women with CDPP:

> *Her perception of her position in life in the context of a culture and value systems in which she lives (*with her social determinants of health, healthcare, rights, and life itself delimited by her gender*), and in relation to her goals, expectations, standards and*

*concerns (*in which she feels dismissed, physically and psychologically at risk, underpaid and unable to work and mother as aspired*).*

That is, are her symptoms, her reduced income, her lack of autonomy all aspects of her QoL or are they determinants of her QoL? (Post, 2014). Research involving people with disabilities indicates that there is no causative relationship between objective functioning and an individual's quality of life, or between the perceptions of patients and able-bodied people, professionals, or others with similar disabilities (Addington-Hall & Kalra, 2001). This apparent disconnect between the level of limitation or poor clinical outcome is evident in women in this study as most measures were negative or reflected lower QoL subsequent to CDPP. However, fewer than half of participants said they would be dissatisfied to live the rest of their lives with their cardiac health as it currently is. By not stipulating a definition of QoL in the survey participants were able to respond according to their own interpretation of QoL.

Patient-reported outcomes and measures for CDPP

As with other aspects of CDPP, there is a paucity of research on QoL, despite the increasing prevalence of CDPP and its associated morbidity and mortality. Patient reported outcomes measures (PROMs) quantify patient’s perceptions of their health and functional status, independent of interpretation by HCPs or researchers (Dawson et al., 2010; Field et al., 2019). In the context of women feeling unheard in healthcare PROMs are of increased importance, providing an additional channel for self-advocacy. Patient reported outcomes (PROs) are integral to person-centred care and essential in improving clinical and QoL outcomes (Rumsfeld et al., 2013). Patient-reported anxiety, depression, perceived health, QoL and distress are independent predictors of subsequent hospital readmission and costs, morbidity and mortality, and knowledge of these factors can aid in risk assessment and resource development and allocation (Rumsfeld et al., 2013; Vámosi et al., 2020). Disease-specific PROMs are optimal (Algurén et al., 2020) and while there are multiple instruments available for various cardiac diseases (Thompson et al., 2016), and for pregnancy and postpartum (Mogos et al., 2013), at present there are no validated PROMs specific to individual or combined cardiac diseases in pregnancy and postpartum. A few studies have adapted existing instruments to fill this gap (Koutrolou-Sotiropoulou et al., 2016). Of the limited data available on PROs for women with CDPP most prevalent were findings of poorer mental health and lower QoL outcomes (Koutrolou-Sotiropoulou et al., 2016).

The results of the modified KCCQ HRQoL were notably lower than generic WHOQoL-Bref, demonstrating a considerable difference when a disease-specific measure is used. Further, this difference may also reflect a degree of acceptance or adjustment. Higher levels of other social and environmental determinants of health that influence QoL such as housing security, and access to healthcare (most people in Australia can access universal healthcare) may affect this score or the HRQoL may be more sensitive to the issues pertinent to participants as it a specific cardiac QoL instrument. The majority of research using the KCCQ involves older individuals with heart failure and include clinical and treatment outcomes, precluding comparison with our cohort of childbearing women (Ravera et al., 2021). However, low QoL and HRQoL are important qualitative indicators as well as being prognostic indicators for further cardiac events and increased mortality risk (Barofsky, 2011; Idler et al., 2004).

Duration of reduced quality of life due to CDPP

The fact that the scores for generic and health-related QoL did not necessarily improve substantially over time, reflects the chronicity of CDPP, and that monitoring, treatment, and support need to extend beyond standard perinatal services timeframes of six weeks postpartum. This is supported by results of a study of women up to ten years following their experience of PPCM that found generalised and cardiac-specific anxiety and quality of life concerns were prevalent in women at all stages of recovery (Rosman et al., 2019). The complex chronic physical and mental health issues experienced by women with CDPP warrant longitudinal studies to better inform care and outcomes. Further, nearly three-quarters of all women surveyed (when only 16% had a genetic conditions) were anxious about their children developing a heart condition, which may reflect both parental anxiety and gaps in understanding of the condition, as well as the level of information and genetic counselling provided.

The results of this study echo research showing that individuals living with conditions associated with sudden cardiac death such as Long QT Syndrome are at increased risk of lower QoL (James et al., 2012; O'Donovan et al., 2020). Adults with implantable cardioverter defibrillators (ICDs) have lower sexual functioning scores, another important aspect of QoL (Cook et al., 2013). Individuals living with genetic cardiac conditions are at risk of lower HRQoL, and higher levels of anxiety and depression compared with population norms (O'Donovan et al., 2020). In addition, experiencing depression, including postpartum depression is associated with lower QoL, physical satisfaction and mental health scores (Papamarkou et al., 2017). QoL may be modifiable with improved communication, psychological interventions and support, increased knowledge and genetic counselling as indicated (O'Donovan et al., 2020).

Broad application of patient-related outcomes research

In an environment of limited research on CDPP, PROs offer an opportunity to enhance researcher and clinician knowledge, clinical outcomes, and QoL for women. The simplest, single global QoL question of *“How would you rate your health - excellent, very good, good, fair or poor?”* has been shown to demonstrate an association between low health rating and a 2- to 7-fold increase in mortality risk and if implemented broadly could have a significant positive impact (Barofsky, 2011). Using PROMs can lead to better symptom recognition which is especially relevant as cardiac disease is under-recognised and under-reported in females (Etkind et al., 2015; Jin et al., 2020; Norris et al., 2020). PROMs enable patients to describe issues or respond to questions about issues that are not usually discussed in routine clinical care assisting them to highlight unmet needs, such as issues identified in this research of partner relationships, sex, death and concerns about their children (Greenhalgh et al., 2018; Higginson & Carr, 2001; Kane et al., 2018; Lavallee et al., 2016; Thompson et al., 2016). The use of PROMs may prompt different communication approaches and content, leading to greater exchange of information, improved patient-HCP relationships, greater referrals and co-ordination of care, as well as increased person-centred care (Chen et al., 2013; Lavallee et al., 2016; Thompson et al., 2016; Velikova et al., 2004). Finally, simply providing feedback through PROs is associated with improved psychological outcomes, HRQoL and patient satisfaction (Chen et al., 2013; Etkind et al., 2015; Velikova et al., 2004).

The results of this study indicate all the above characteristics of PROMs are desirable and may address the negative aspects of their PROs; however, this is dependent on the attributes of the PROM. A review of the literature and trends in PROs found that there has been an increase in the reporting of sex and gender differences in disease prevalence, treatment tolerability and overall treatment outcomes in the last years, however this remains under-developed (Hertler et al., 2020). Information on sex- and gender-specific aspects in PROMs has remained sparse and has not been optimised for the needs of women with CDPP, especially in capturing issues concerning fertility, breastfeeding, and being a mother. A content comparison of 34 cardiac disease PROMs found a preponderance of PROMS related to physical and emotional functions, with no explicit mention of issues related to parenting or mothering which was paramount for the women in this study (Algurén et al., 2020). Similar findings have been reported for pre-eclampsia (Duffy et al., 2019). A systematic review of research on cardiac disease in pregnancy found 94% of studies reported only on clinical or adverse effects and none included PROs on QoL impact and functioning (Hall & D'Souza, 2020). However, pregnant women with cardiac disease want QoL included as a PRO and this should be incorporated alongside the more clinically based outcomes (Hall & D'Souza, 2020; Parsonage et al., 2020). The CDPP-specific questions in our survey were the items that had the strongest responses, highlighting their importance to participants.

11.2.6 The needs of women with CDPP

Research question 5: *What are the needs of women with CDPP?*

Consistent with the lack of data on women's experiences and QoL outcomes, there is a paucity of data on the specific and complex needs of women with CDPP during their pregnancy or cardiac event and ongoing.

Many participants in Study 1 wanted to improve healthcare and support options for girls and young women with pre-existing cardiac disease and women with CDPP, and this was a key motivation for their involvement. This desire was reiterated in Study 3 (focus groups). Some women in both studies had already contributed to other research, been involved in advocacy and public awareness activities, and sought to provide support to other women when possible.

Using the information gained from Study 1, a brief needs assessment was developed and included in Study 2 in which participants were asked to rate the helpfulness of suggested possible support and resource options as *"Not useful at all", "Somewhat useful", "Useful",* *"Very useful",* or *"Extremely useful".* The options were: peer support, cardiac link nurse, counsellor, a website on their condition, a CDPP website or a page on a related cardiac disease site, public Facebook page for their condition, private Facebook group for their condition, printed resources with health tips, and printed resources on their condition.

There was support for all options in the needs assessment with *strongly positive* responses for peer support, counselling and a cardiac link nurse. Peer support scored highest with 70% of participants rating it as very useful or extremely useful and no participants rating it as not useful. The recommendation of peer support programs, integrated counselling and a cardiac link nurse being available to all women, directly addresses the key research findings of women's isolation, poor mental health, knowledge gaps, and the perceived shortfalls in their healthcare experiences. That is, peer support responds to isolation that is exacerbated through lack of specialised services, fragmented care and lack of acknowledgement of mental health needs; counselling integrated into routine care recognises the need and responds to the fact little or none was offered; and a cardiac link nurse is in response to the lack of information and resources women received as well as the lack of continuity and coordination of care. These findings are supported in the literature on where health-related peer support or mentoring programs that are specific to the needs of women (including preconception, pregnancy and postpartum concerns) are desired and valued by cardiac patients (Bouchard et al., 2021).

Women described having a steep learning curve when they were diagnosed with cardiac disease or when managing pregnancy and postpartum with a cardiac condition. Many women with new diagnoses have had minimal health concerns previously and largely only interacted with health professionals and services about routine reproductive health needs, so may not have developed high health literacy or skills in self-advocacy. Further, it is impossible to have high health literacy for conditions where there is little information available. Women have to absorb complicated, technical or vague health information with variable quality of communication from HCPs when medically unwell and emotionally distressed, often while navigating the early days. Being a mother adds another dimension and complexity, physically and mentally, as the women were trying to care for themselves while still unwell and recovering while also caring for babies and often other young children. Partners, family and friends may have difficulty understanding the significance or ongoing impact of women's experiences, especially as the “look the same” or are still able to perform most activities of daily living. Partners of the women in this study were also reported to experience a range of emotions and challenges, and need their own support, as shown in previous research (Patel et al., 2019). Further, partners may not able to provide the type of support that the women require. In summary, more professional clinical, psychological and social support is required.

Allied health services also need to be incorporated into routine care and referrals, e.g., exercise physiologist, physiotherapist, rehabilitation, dietitian, and occupational therapist (especially relevant when women are instructed not to lift anything over a couple of kilograms, including the baby or other children, and no support was provided in how to manage that). Having counselling and referral to peer support and a cardiac link nurse incorporated into clinical guidelines and routine care will be especially important to ensure equitable access to services for women who may otherwise not be aware of these options, including women with reduced English language and reading literacy, no smart phone or use of social media. There is a need to cater for diversity as women with CDPP are a unique demographic and have different cardiovascular and psychological profiles to older rehabilitation patients, and programs need to be designed to meet the needs specific to them (Neubeck et al., 2022).

Finally, it is important to involve women in the co-design of future research projects and resources as the experts in their needs. The literature supports the requirements for specialised resources and support for women in pregnancy (Costa et al., 2015), postpartum (Almalik, 2017), following severe maternal morbidity (Hinton et al., 2015b) and following a cardiac event and diagnosis (Ebrahimi et al., 2021). The findings in this research provides service providers, funders and researchers with valuable data to inform future research and project design.

11.3 Implications of study findings

11.3.1 General implications

Cardiac disease in pregnancy and the first twelve months postpartum is an important health issue that is associated with maternal mortality, acute and chronic cardiac and mental health morbidity, and reduced quality of life for affected women. By extension, these outcomes for women have implications for the partners, children, other family and friends, and wider occupational, economic and other participation in society.

International prevalence estimates for CDPP range from 1% to 4% of all pregnancies (Regitz-Zagrosek et al., 2018) and up to 16% of pregnancies in women with previous cardiac conditions (Silversides et al., 2018). This translates to approximately 3,000 to 12,000 women annually in Australia (Australian Institute of Health and Welfare, 2020a). This figure likely under-represents the data due to reporting issues, not including postpartum to 12 months, and under-recognition and under-diagnosis of cardiac conditions (England et al., 2020). Prevalence is rising due to increasing survivorship of children born with CHD, increasing rates of cardio-metabolic disease, rising rates of older mothers, newly defined conditions and improved diagnostic processes in some conditions (McClure et al., 2011; Regitz-Zagrosek et al., 2018). Thus, while some individual diagnoses within the combined CDPP may be rare (prevalence of less than 2 per 1,000 people, such as arrhythmogenic right ventricular dysplasia), not all conditions are rare or uncommon, and combined CDPP is likely to occur in a significant number of Australian women.

In Australia, cardiovascular disease was the leading cause of maternal death between 2010 and 2019 and was responsible for 14.0% of all maternal deaths and 28% of indirect maternal deaths (Australian Institute of Health and Welfare, 2021a). Maternal deaths that are recorded only up to 42 days postpartum omit late presenting cardiac cases, in particular pregnancy associated spontaneous coronary artery dissection (PSCAD) and peripartum cardiomyopathy (PPCM), thus the mortality data may be under-representative.

Maternal morbidity is also significant with up to 23% of women with cardiac disease hospitalised during pregnancy (Roos-Hesselink et al., 2013) and for every death up to 8 women have severe maternal morbidity (Huisman et al., 2013). The literature shows that of women who have cardiac disease in pregnancy, 17% will also have obstetric complications (Roos-Hesselink et al., 2019) and 18-30% will have associated foetal/neonatal complications (Siu et al., 2001). The small body of literature relating to mental health outcomes of CDPP indicate increased risk of anxiety, depression, PTSD and that these conditions persist for the duration of 10-year studies, and feasibly beyond this timeframe (Johnson et al., 2020; Pfeffer et al., 2020; Rosman et al., 2019). There is a bidirectional relationship with cardiac disease and mental health conditions in both associated risk and poorer outcomes (O'Neil et al., 2021).

Another critical issue to consider is the degree of preventability of adverse clinical outcomes. Research on all-cause maternal morality found that 68% of maternal deaths had at least one severe maternal morbidity indicator, and suggested that earlier recognition and intervention would reduce both morbidity and mortality (Ray et al., 2018). Studies on contributing factors to preventable maternal death, including for CDPP, identified HCP factors (symptoms not recognised, referral and treatment delayed or didn’t happen) in 33.9%-60.0% of cases, health system factors (lack of resources and infrastructure) in 21.6%-47.0% of cases, and patient and family related factors (pregnancy against medical advice, underestimation of symptoms) in 12%-40.0% of cases (Building U.S. Capacity to Review and Prevent Maternal Deaths, 2018; Geller et al., 2004; la Chapelle et al., 2012; Lameijer et al., 2020). Results of this research illustrate examples of each of these modifiable risk factors for maternal morbidity; HCPs, health systems and women and their families. Preventable adverse outcomes also affect foetal and neonatal outcomes, especially for cardiac disease in pregnancy. For example, the rate of prematurity associated with PAMI is three times higher than in women without PAMI and causes are commonly iatrogenic (Burchill et al., 2015; Cauldwell et al., 2019).

This very brief summary of CDPP prevalence and outcomes highlights the significance of CDPP to women and their families, health services and professionals, researchers and policy-makers, and this will be elaborated on below. It is noted that there are numerous implications and recommendations which reflects that CDPP is currently under-researched, which in turn affects health systems and clinical care.

11.3.2 Implications for the health care system

The findings of this study include important implications for health services design and delivery. Health services were experienced as fragmented and lacking coordination. A lack of clinical guidelines and referral pathways meant women had to act as liaison between specialists, hospital and general practices. These attempts to be the intermediary were mostly unsuccessful and led to frustration, and reduced communication of medical and obstetric conditions, management and recommendations, and poorer outcomes. In particular, there appeared little involvement of anaesthetics in planning discussions and assessment even for planned epidurals and caesarean births. When women were referred to tertiary hospitals, returned to rural or private hospitals, or discharged to the community the information provided was lacking. For example, one woman was flown from a rural/remote hospital to a metropolitan tertiary hospital immediately after a caesarean birth because she was in severe heart failure; once there she was given no information on her condition and had to request the cardiologist return specifically to tell her what her diagnosis was before she returned to the original hospital. She received no description or information, no links to support services or websites such as the Heart Foundation, and once she was stabilised she was flown back within 36 hours to the rural/remote hospital where the hospital staff had no experience of PPCM. The lack of continuity of care, effective handover and communication affected the care she was provided and significantly added to her distress. Other examples include women with congenital heart disease (CHD) who described the process of transitioning from paediatric to adult CHD care as inconsistent and lacking co-ordination; and when most women with any CDPP attended their general practitioner (GP) for review and follow-up post-discharge the GP had often received no discharge summary or referral information to guide them, and may not have experience managing their condition the women were presenting with. Fragmented care defined by postpartum admission within sixty days of birth admission discharge to a hospital different to the birth hospital is associated with increased risk of severe maternal morbidity, length of stay and hospitalisation costs, though this is at times unavoidable (Wen et al., 2020). Hospitals that had both cardiology and maternity services did not necessarily co-ordinate care either, and adherence to the baby-friendly hospitals initiative was not evident in most cases.

Health service fragmentation and referral also affected mental health services, rehabilitation and allied health, all of which were almost exclusively absent from the care women received, despite evidence of need in the literature and despite women expressing their need (for example, scores indicating depression of the Edinburgh Depression Scale screening yet no intervention or referral provided). It is noted that a recent review of cardio-obstetric competence and workforce planning recommended cardio-obstetric team of medical specialists, pharmacists, geneticists and social workers, with no mention of psychologists/counsellors, physiotherapists, dietitians, occupational therapists or nurses and midwives (Sharma et al., 2020). This very limited multi-disciplinary team would not meet the needs of women as described in this research, and omits the professional groups who arguably have the greatest contact hours with patients, nurses and midwives, and are thus a crucial resource for patient education, referral and support. The literature supports the development of cardio-obstetric and co-located services (Davis et al., 2021; Magun et al., 2020; Quiñones et al., 2021), and endorses the requirements for specialised resources and support for women in pregnancy (Costa et al., 2015), postpartum (Almalik, 2017), following severe maternal morbidity (Hinton et al., 2015b) and following a cardiac event and diagnosis (Ebrahimi et al., 2021).

11.3.3 Implications for research

CDPP is under-researched internationally, and within Australia, there is only a small number of studies on specific conditions. There is currently no national epidemiological data and no or little research on the clinical characteristics, management and outcomes of cardiac diseases in pregnancy and postpartum to help inform service and infrastructure planning, clinical education, the development of clinical pathways and guidelines and resources for affected women and the community.

This study found that the concerns of foremost importance to women were their experiences mothering, having more children, and of being autonomous in making such personal and important decisions, and these concerns often superseded considerations about their cardiac health. There is little but growing research based on the pregnancy and cardiac outcomes of having a subsequent pregnancy, with some evidence suggesting that for CHD the key predictor of cardiac issues in subsequent pregnancies is cardiac outcomes of the previous pregnancy (Furenäs et al., 2020), modified WHO classification of maternal cardiovascular risk (mWHO) class (Steiner et al., 2021) and obstetric complications (Kloster et al., 2022). Further, preliminary research suggested no additional cardiac risks for women to have a subsequent pregnancy after a SCAD or PSCAD (Tweet), however fewer positive outcomes for women who have a subsequent pregnancy following PPCM (Hilfiker-Kleiner et al., 2017). If a woman does have subsequent pregnancies, there is scant research on what management strategies may moderate risk, to what extent, and the acceptability of these interventions and risk to both women and their HCPs. The women in this study were mostly advised to not have future pregnancies, and when a rationale was provided it was that the risk was too high, though that risk was not quantified or explained, and women felt there was a distinct lack of an evidence-base for this advice which may have made accepting the advice more difficult. Adding to the distress of having no more children, women joined international heart forums and read about women in other countries being successfully supported through subsequent pregnancies, though the long-term outcomes are yet to be realised. Further research in this area will allow for more nuanced, individualised care.

The results of this study highlighted a lack of evidence-base to inform decisions about medication safety in breastfeeding, with the starkest example being a woman who was told to breastfeed whilst taking betablockers but that if her baby turned blue then to stop breastfeeding; this is not satisfactory advice especially to a woman who had a near-death experience due to a cardiac arrhythmia. Further, this study is consistent to previous data showing that women highly value breastfeeding as being more than nourishing their child, but being critical to bonding and connection (Burns et al., 2010). Mirroring the advice to not have further children, the advice regarding breastfeeding was lacking a clear research-base, making difficult situations more so.

Whilst contraception was not a specific focus of this study, it was an issue raised by women who reported being given little or no advice from their cardiologist on contraception other than it was imperative to use it. Further, their GPs frequently had no experience of prescribing to this cohort of patients. There is limited data on the most appropriate contraception for the various cardiac diseases experienced by women with CDPP (Jakes et al., 2018; Lindley et al., 2021) though the WHO medical eligibility for contraception guidelines are available (World Health Organization, 2015). The focus thus far has understandably focused on contraception efficacy, safety and risk (Sobhani et al., 2019), however increased focused now needs to be applied to ensuring that contraception counselling is included in care-planning, seeking to understand and respecting women's preferences and values, and effective communication; that is, taking a person-centred approach (Parsonage et al., 2020; Tromop-van Dalen et al., 2021).

The results of this study echo previous research on young women being less likely to be referred to cardiac rehab than any-age men, despite them being the cohort most likely to gain the most benefit from rehab (Colbert et al., 2015; Colella et al., 2015). There is minimal research on the cardiac and mental health value of rehab programs for women with CDPP, and the participants in this research received varying and at times contradicting advice. These younger women may not require the degree of physical fitness rehab and training as an older person; however, they very explicitly wanted a rehab service in which to resume physical activity with safety. Their primary objective was to help re-build their damaged body-trust and confidence in themselves, and this was an important aspect of managing their post-CDPP anxiety and defining their new normal. Recent research confirms the need for cardiac rehab research and services that are specific for the physical and psychological needs of participants, and addressing that current programs developed for older cohorts with different diseases, needs and goals do not meet the needs, and are too restrictive for young mothers (Bouchard et al., 2021; Ferguson & Kovacs, 2016; Neubeck et al., 2022).

This study is the first to examine women's healthcare experiences, mental health, general and HRQoL, and the effect of having CDPP on women's experiences mothering for the combined CDPP cohort. It adds to the few existing studies on QoL and HRQoL for PPCM and CHD and found that women had a marked reduction in generic QoL, and an even greater reduction in HRQoL (Koutrolou-Sotiropoulou et al., 2016; Rosman et al., 2019). The average time since their CDPP for both Study 1 and Study 2 was around 5 years, demonstrating a persistent reduction in QoL. Additionally, the new questions developed for this study provide new data on the significant impacts of CDPP on women's career options and financial concerns (including ability to pay for ongoing specialist care).

The women in this study women want QoL and HRQoL to be included in clinical care and research, confirming earlier research (Duffy et al., 2019; Hall & D'Souza, 2020). The use of multiple QoL instruments in Study 2 accentuated the limitations of using general QoL instruments, and of using existing cardiac QoL instruments that have largely been developed for older populations who are more likely to have co-morbidities, multiple medications and who likely have very different life goals and expectations than a 30-year-old woman with a baby. These existing cardiac QoL instruments rarely include issues about relationships and sex, and no instrument was found that included the experience of mothering with cardiac disease.

One of the more significant findings of this research is the negative impact of CDPP on women's' experiences mothering. This included the effect of physical limitations due to their condition and inability to mother in the manner they expected to and want to, and the impact on their mental health outcomes. An additional novel finding was the impact of CDPP on women's relationships with their partners; this ranged from very strongly positive to very strongly negative, with a negative impact on their sex life and feeling about themselves and outlook.

The literature is established on the bidirectional relationship between cardiac disease and mental health, with associated increased morbidity and mortality, excess utilisation of health services, and worsening of cardiac and mental health outcomes if not treated and supported (O'Neil et al., 2021). This research revealed that mental health concerns were dominant and persistent for women with CDPP, signposting the ongoing cardiac and mental health risk for women. There is a lack of data on what mental health interventions would be most effective, acceptable and realistic for this population of women with infants and young children who are recovering from a combination of traumatic births and cardiac events, acute health crises and trying to mother their children.

Finally, this study highlights how acutely isolated the women felt, and that this isolation exacerbated the mental health conditions and potentially disadvantaged them from not accessing information about their condition. There is scant research on what support options would be most appropriate and effective, however this study found strong support for organised peer support, and this could be modelled on existing programs for other populations.

11.3.4 Implications for healthcare professionals

A central finding of this study was the pervasiveness of women feeling dismissed and not listened to by HCPs. This was experienced from all disciplines, specialities and in all clinical settings, for all cardiac conditions and timing of diagnosis. The impact of this was delayed and incorrect diagnoses, distress and trauma for women, loss of trust in HCPs and a loss of trust and confidence in themselves, as seen in previous research (Dekker et al., 2016; Hess & Weinland, 2012).

In addition to dismissiveness, the communication style and interactions with HCPs did not always reflect PCC, shared decision-making, or respect of patient rights or values. Communication was most often received as overly brief uni-directional instructions; there was limited inquiry on cardiac signs and symptoms and close to no inquiry into her needs, questions she had, values, or concerns. Women were told to cease breastfeeding and no advice or support was given to support that process, and they were told to not lift their babies but received no suggestions for how to manage being home alone caring for her baby and other children without lifting. Discussion on contraception was lacking, including no consideration of religious or other values or past contraceptive experiences.

The results of this research emphasise the importance of decision-making and autonomy for women, especially for the deeply personal and important decisions about having children and breastfeeding. The communication on these issues was not adequate, often with no counselling support offered for what women described as distressing and "*devastating*" conversations.

Clinical knowledge was clearly affected by limited research on CDPP, and the lack of clinical guidelines or pathways meant some women experienced inconsistent, sub-optimal care. When guidelines were available it was not clear they were followed, as found in previous recent Australian research on compliance with cardiac guidelines in pregnancy (Millington et al., 2020). General clinical skills were also at times lacking, for example the inability to perform or interpret ECGs, inadequate history-taking and lack of response to clinical deterioration even when objective signs were apparent and documented, which is a risk factor for preventable severe maternal morbidity. The impact of the lack of research and education on cardiac disease in young women, especially CDPP, on clinical practice is summarised in the experiences of one participant who had a PSCAD a few months postpartum. In the emergency department (ED) she had intense and worsening central chest pain that radiated down her right arm, minimal ECG changes, and increasing blood pressure. She had two positive troponins which the ED staff determined were both false positives because she *"did not fit the picture*" of someone having a heart attack (based on the pain being in her right, not left arm, and her age and gender), and a radiographer was called in at 3am to conduct a CT to exclude a pulmonary embolism. After the negative CT a third troponin was performed which showed significantly increasing levels and she was transferred to a tertiary hospital, still with unresolved chest pain after 12 hours. The question is *"which picture was it that she did not fit*?" A picture of a 70-year-old overweight man with longstanding ischaemic heart disease having an atherosclerotic myocardial infarct? Or the picture of a 30-year-old postpartum woman having a PSCAD? *If there is no research or education, or case scenarios and thus no "picture", how can she or other women with CDPP ever match it?* Further, *guide*lines and clinical pictures *guide* practice, and should not be used rigidly without critical thinking and assessment of the patient in front of you, not a picture of someone else.

Another key finding of this research was the severity and persistence of poor mental health, with many women describing the mental health outcomes being worse than the cardiac outcomes. Women's mental health suffering was complex and layered and included grief, anxiety, depression, trauma and PTSD. Women who struggled for years to conceive now faced having to destroy their frozen embryos in IVF clinics. Some women suffered estrangement and distress communicating genetic conditions to immediate and broader family networks. They knew or feared they had passed the condition on to their children, were anxious for their children's health and futures, and feared not living long enough to raise them. Their marriages and partnerships, roles and aspirations were all altered, and they felt alone in navigating these complex phenomena. They often felt incredibly isolated as a mother with cardiac disease which exacerbated their anxiety and depression. When they were well enough to attend mothers' groups it was usually triggering and alienating, thus they often did not continue to attend. However, they needed connection and that was most valued from other mothers with similar conditions, or even any chronic health condition. Their mental health concerns were almost exclusively not recognised or responded to by HCPs, and referrals to counselling or other support was rare. Women were appreciative of supportive interactions by other HCPs, but they required and wanted mental health care by qualified mental health professionals, ideally someone with additional expertise in trauma and chronic health issues in younger people.

Other referrals desired and not received were for occupational therapy to manage the physical limitations of their cardiac condition and caring for an infant and sometimes older children. They wanted cardiac rehab to help build their confidence and trust in their bodies and reduce their health anxiety. They also wanted nutrition advice, primarily to cover all bases as they largely had no traditional cardiac risk factors, were of a healthy weight, ate a nutritious diet and exercised. Having this input from allied health would have aided in specific practical issues and helped the women regain confidence.

Another significant finding was the lack of acknowledgement or response to the issues that were critical for women; mothering, having more children, being able to breastfeed, being informed and included in decision-making, and to be heard. As outlined above, women had an ongoing reduction in general QoL, HRQoL, mental health and most had ongoing physical restrictions from their cardiac condition. They had reduced income and career options, reduced social interaction, loss of involvement in team sports and changed relationships. In their non-obstetric healthcare, their status as mothers was nearly always an afterthought or missing altogether. Women who had just survived an acute cardiac event and were breastfeeding or using a breast pump were in wards shared with elderly men and had little privacy. Recommendations for physical restrictions (such as not lifting anything more than 3 kg, not walking more than 500m) did not come with acknowledgement or suggestions for managing a newborn and toddler. In their obstetric care women felt their cardiac condition was outsourced in toto and thus it was not discussed, or when it was, the women's expertise in her condition and attempts to relay information and advice from her cardiologist was typically not heard or incorporated into care. Their experiences of cardiac care were similar, and ultimately, they felt dismembered by the fragmented health care system and siloed practices of HCPs that offered no continuity of care or recognition.

Advice to attend multiple appointments, at times in different locations, with no close parking, did not account for a woman who should not walk far, or carry or push her children in a pram, nor was it responsive to the challenges of taking children to medical appointments. Most ongoing cardiac care was in the private sector and women who now had reduced or no income at items struggled to afford attending important check-ups, including for implantable devices.

A final important finding from this research relating to clinical care and HCPs, is that most women recognised that most HCPs were doing the best that they could in an under-resourced and under-researched clinical area, but the women nonetheless needed more than what was provided.

11.4 Recommendations

The paucity of previous epidemiological, clinical and qualitative research in CDPP in Australia means there are numerous recommendations to evolve from this research. The key recommendations are numbered and are followed by additional recommendations and options.

11.4.1 Over-arching recommendation

Involve women with CDPP from diverse backgrounds in the co-design of resources services and research. In particular, it is imperative to include culturally diverse women who are currently under-represented in research.

11.4.2 Recommendations for the health care system

The majority of my recommendations are for government, public and private health services including non-government organisations, and policy-makers. Expanding funding of research and health services leads to better clinical and QoL outcomes. This contributes to a reduction in avoidable post-discharge health service utilisation, re-admissions, and better use of ancillary and allied health services. Some of the following recommendations are broad as this research did not explore the details of these systems or issues, rather this research examined the impact of the current status of healthcare on women with CDPP. Further, many of these recommendations are dependent on research being conducted.

Recommendation 1

Fund further research (see below) to inform the majority of the following recommendations.

Recommendation 2

Establishment of a national CDPP reference group to develop and guide recommendations from research (including but not limited to service design, research priorities and implementation, clinical pathways and guidelines, and education). This would include consumer and patient lived experience.

Recommendation 3

Enhanced co-ordination and continuity of care. Consideration of colocation of services and if warranted by prevalence data, additional cardio-obstetric services. In the absence of co-location, consideration of formalised referral pathways and connections, especially for rural and remote areas. Inclusion of general practice, community nurses/midwives and allied health in these referral pathways.

Recommendation 4

Development of clinical guidelines, including for general practice and community nurses/midwives and allied health (with the caveat of noting there is a research deficit in some areas and the guidelines need to be viewed as such). Key inclusions that could be implemented before significant additional clinical or epidemiological research is undertaken are referral pathways for rehabilitation and mental health to be integrated into routine care.

The integration of mental health support as 'business as usual' was highly valued and desired by the participants in this research.

Recommendation 5

Extended postpartum screening for mental health conditions (i.e., beyond 6 weeks, and not limited to anxiety and depression).

Recommendation 6

Examination of specialist models for the provision of cardiac rehabilitation to mothers who have infants and small children. For consideration is remote access to specialised metropolitan services and education modules for regional, rural and remote rehab services. An additional consideration is increased focus on the mental health aspects of rehab for this cohort and possible involvement of mental health professionals in rehab programs.

Recommendation 7

Development of resources for women with CDPP. This could include separate websites or dedicated sections on existing cardiac organisation websites. Development of written material available for women and their families at time of diagnosis and any later cardiac intervention and surgery.

Recommendation 8

Education on cardiac disease in younger women and CDPP in particular to ED, GP, maternity, child and family health nurses, cardiac staff, rehab staff, allied health and ambulance/paramedic staff. Ongoing education for assessment skills and use of basic equipment, especially outside specialty areas (e.g. ECGs in general wards and maternity units, breast pumps outside of maternity units).

Additional health systems recommendations and options

- Review of ongoing cardiac care models, costs to patients, and physical accessibility issues.
- A review of the baby-friendly hospitals initiative to include non-breastfeeding mothers of babies in hospital.
- Review the provision of mental health support for teens, especially when transitioning to adult cardiology, and during preconception planning for women with pre-existing disease. The transition process from paediatric to adult cardiology was felt to be sub-optimal in relation to cardiac care, mental health, contraception advice, and preconception planning.
- Provide training and support for moderators of Facebook groups. Develop and provide guidelines on safely engaging with, and getting the most out of online groups.

11.4.3 Recommendations for researchers

Recommendation 1

Establishment of a CDPP reference group to develop and guide research questions, study design, and implementation.

Recommendation 2

Undertake nationwide epidemiological and clinical characteristics research on all cardiac disease in pregnancy and the first 12 months postpartum (potentially to 24 months for PPCM and PSCAD) as a priority. This is a critical step to provide data for many of the rest of the recommendations.

Recommendation 3

Undertake nationwide longitudinal research on clinical, mental health and quality of life outcomes for women with CDPP and their offspring.

Recommendation 4

Develop a pilot project to provide a structured peer support program for women with CDPP that includes women whose experiences are recent through to many years ago. Existing models such as that used by the Cancer Council NSW can provide a template.

A structured peer support program was highly valued and desired by the participants in this research.

Recommendation 5

Develop a pilot project of a cardiac link nurse who is available to all women with CDPP (i.e., not limited to one hospital or area, or diagnosis). A pilot program could be developed that either expands the current scope of an existing localised service (e.g., one provided by a heart failure clinic in one health district), and or it could be modelled on other services such as cancer care (e.g., Leukemia Foundation or Cancer Council helpline).

A cardiac link nurse was highly valued and desired by the participants in this research.

Additional research recommendations and options

- General cardiac research (i.e., research not specific to CDPP) to include pregnancies and births as part of the participant characteristics.
- Develop and validate a new PROM/s for CDPP. There may be a component applicable to all cardiac conditions, and then additional disease- and timing of diagnosis-specific

sections. Include aspects such as relationships and career/finances plus either a significant component relating to mothering, or develop and validate a separate new PROM/s for mothering with CDPP.

- Research on contraception and preconception care for women with pre-existing cardiac disease.
- Research on the management and outcomes of subsequent pregnancies.
- Research is needed to examine the experiences and needs of diverse groups addressing social and environmental determinants of health and intersectional barriers and influences to care and outcomes (Lindquist et al., 2015).
- Acknowledging the challenges of conducting clinical research on breastfeeding women, there is scope to conduct additional research on the risks of the most commonly prescribed cardiac medications for women with CDPP, and develop a pre-treatment screening tool (e.g., checking family or personal history or arrhythmias prior to prescribing domperidone).

11.4.4 Recommendations for healthcare professionals

The recommendations presented here acknowledge the context and impact of the global pandemic on individual HCPs and health systems, and that those systems risk being dehumanising in nature. It is difficult to extend oneself from a place of depletion and when operating in survival mode. It is also difficult to be creative and innovative when fatigued, and if feeling unsupported, under-resourced or unfairly treated in the past few years.

It is my belief that health systems and research enable excellent care; thus, the following recommendations are less likely to be realised without the above recommendations being adopted. That said, being enabled is only the first step and action is still required by HCPs in number of areas, not least of which the issue of being dismissed by healthcare professionals was the strongest healthcare theme in this research.

Recommendation 1

Listen to women.

Do not dismiss them, their signs and symptoms and expressed distress. Value their knowledge of their own bodies, and their expertise in their cardiac conditions (in particular, for women with longstanding disease).

Recommendation 2

Clinical discussions regarding difficult or sensitive subjects may be better managed by adapting existing guidelines in fields of infertility, sexual health, and cancer care (for discussion of serious chronic illness).

Recommendation 3

Provide clear information (verbal and written) about their diagnosis, self-management, medical care and prognosis (as able with limited research). Update this when there is new information on the condition, treatments or changes in their cardiac status due to treatment, deterioration, pregnancy or other factors.

Recommendation 4

Work collaboratively and provide coordinated care cross disciplines and specialties. Refer to other HCPs as above, especially mental health.

Recommendation 5

Ask and listen, and read research that describes the issues that are important to women, including not being able to have more children, decisions about genetic and cardiac testing for their children, concerns regarding reduced longevity, and issues concerning mothering after a cardiac event and ongoing.

Recommendation 6

Undertake relevant education and training to maintain currency in core competencies, and to develop competencies in specialty areas based on one’s profession.

11.4.5 Comments regarding women who have had CDPP

Women in this research described not asking for help, not wanting to be a drain on the system by calling an ambulance (while they themselves were mid heart-attack), and putting the needs of their children and partner ahead of their own at a cost to their health. Acknowledging the caveats about not expecting the least powerful in a system to be the ones to drive change (the patients, especially those who’ve experienced racism and additional bias and abuse), there is still a need for women to be empowered to engage differently. This is about a broader conversation about self-worth, being able to ask for what you need, identifying systemic barriers and gathering support. This is beyond the scope of this thesis, but it is important to note.

Finally, women with CDPP have actively contributed to this research and other research, advocacy, public awareness and support roles; this has been invaluable to these projects but most importantly for other women with CDPP now and in the future. The value of their continued engagement is inestimable.

11.5 Strengths and limitations of this study

A methodological strength of the study is the use of a mixed methods study design. By incorporating both qualitative and quantitative approaches and data, the research produced a breadth and depth of findings on a variety of experiences and issues pertinent, and important, to women with CDPP that would not have been possible with a singular research approach.

This research is the first to my knowledge that included: a diversity of diagnoses across acquired, congenital and genetic heart disease categories, CDPP up to 12 months postpartum, a range of time since CDPP (from 8 weeks to 10 years), a range of timing of diagnosis (from at birth to early forties) and inclusion of presentation of cardiac disease before and during pregnancy and postpartum. The extended timeframe to 12 months postpartum is particularly relevant for PSCAD and PPCM where late postpartum cases are diagnosed up to a year postpartum. The range of time since CDPP allowed an informal comparison across time and to note the persistence of poor mental health and quality of life outcomes. This diversity also provided the opportunity to make informal observations of similarities and differences between diseases. Further, by including women with all cardiac disease except hypertension and pre-eclampsia, I was able to include women with rare diseases who otherwise may not be included in any disease-specific research due to inadequate numbers.

The use of a diversity of PROMs captured a broad range of data and the new questions that were developed revealed important outcomes not previously recorded in the literature.

The majority of women with CDPP interviewed in our study had not debriefed their experiences, and the opportunity to narrate their story unscripted and unconstrained was enlightening for many of them as they reflected upon their own distress and recovery, and clarified their goals for themselves and future girls and women.

In addition, surveying patients close to a health event can lead to a distortion of results with survival gratefulness and optimism being overstated, and the effects of attempting to re-enter life, resume normal functions, work and social interactions, and in the case of CDPP, embark on mothering with a cardiac condition, may not yet be fully realised and thus unable to be captured at this early stage (Åberg, 2020). Including women with a range of time since their CDPP provided a view across time and could address this issue.

A final strength is that I am a health professional with four decades of experience, however I am not aligned with any of the HCPs, specialties, disciplines or health services in this research. This facilitated a deep understanding of issues presented by women, the perspectives of HCPs and issues of health systems while avoiding any bias.

A methodological limitation is that participants may be subject to recall bias, both positive and negative, especially for those whose experiences were many years ago. The generalisability of findings is limited to English-speaking patients with no representation of Australian First Nations women, women from non-English speaking backgrounds, and no participants identified their sexuality or if they were living with a (non-cardiac) disability.

The study population was relatively small, and the diversity of conditions, cardiac disease severity, parity, number of affected pregnancies, age, gender-identity, ethnicity and other variables are unknown; therefore, a social media recruitment protocol was developed with the aim to reach as many affected women as possible. The majority of interviewees responded to social media recruitment strategies, and the limitation of this is that women not using social media are unlikely to be included in this study. While including a range of cardiac diseases is a strength, it is also a limitation, in particular when consideration is to be given to responding the needs identified. More studies are needed to understand specific needs of women with CDPP, including the needs of diverse populations and changing needs over time. Finally, recruitment numbers for the quantitative survey were insufficient to perform statistical analysis (beyond descriptive analysis) and to be considered representative.

These limitations notwithstanding, this program of research contributes valuable insights to the small body of knowledge on women’s experiences, values, outcomes and need relating to CDPP.

11.6 Chapter summary

Chapter 11 outlines the key discussion points that have arisen from this research, namely that there is a lack of PCC and that health care services and HCPs are not reliably meeting the needs and expectations of women with CDPP. Additional points are that women have reduced mental health and quality of life subsequent to CDPP, and that their experiences of mothering are negatively affected. In addition, participant-identified needs are described. Implications and recommendations were described for the health care system, research and healthcare professionals, and study strengths and limitations were defined.

The following chapter will provide the conclusion to the thesis.

Chapter 12: Conclusion

This thesis presents the results of an investigation of the experiences and needs of women who had cardiac disease in pregnancy and the first year postpartum (CDPP). The data for this research was from multiphase exploratory sequential mixed methods research design including three studies; qualitative interviews, a quantitative survey, and qualitative focus groups. This study has produced a number of key findings.

First, this research identified a lack of person-centred care (PCC) and common themes of feeling dismissed and powerless in the health care system. Regardless of women's individual attributes, knowledge and experience, self-advocating for their health is complex and difficult. The inability of women to have their voices heard had negative cardiac and psychological outcomes. Person-centred care places a requirement on health systems to provide an adequately resourced and culturally safe environment where healthcare professionals are supported to provide person-centred care.

Second, women's healthcare experiences did not meet their expectations or needs. Care provided was reported to be fragmented and lacked co-ordination. Results identified a lack of responsiveness of the healthcare system in providing fit for purpose health care for women with complex disease who are pregnant or new mothers. Of concern is that this equally applies across pre-existing and de novo diagnoses, reflecting a lack of responsiveness of the healthcare system to providing care.

Third, these findings provide a unique insight into women's mental health experiences and challenges across a spectrum of cardiac conditions and timing of disease. Most women in this study did not report isolated or singular trauma or distressing event, rather there was a layering of traumatic experiences, and the number, nature and recovery from previous traumas informed and complicated the trauma associated with their cardiac disease in pregnancy and the postpartum period. Acknowledging and understanding this breadth, complexity and depth of women's experiences of CDPP is a fundamental step in improving outcomes.

Fourth, it is evident that CDPP has a significant negative impact on the quality of life (QoL) and health-related QoL (HRQoL) on women with CDPP. Participants had CDPP on average five years prior to participating in this research inferring a persistent negative outcome. Responses to their diagnosis, advice to avoid future pregnancies, concerns about their longevity and their children's health suggest a role for increased and improved counselling, communication and information, with a need for clinical and qualitative research to inform these. Access to healthcare is compromised by a lack of access to childcare and consultation costs. This in turn reflects increased cardiac risk due to the inverse relationship of lower QoL, mental health and reduced access to care and cardiac injury or deterioration.

Fifth, for the participant their role as a mother superseded all other considerations, and her needs as a mother were not acknowledged or met. Further, while the findings include positive aspects, the majority of themes and experiences were negative, or mixed. In the acute stages women felt unseen as mothers, and they had enduring physical limitations and mental health concerns due to their cardiac condition. Women’s potentially reduced longevity, their ability to mother, concerns about their children’s health and intimate relationships were important, as was the advice to cease breastfeeding and to avoid future pregnancies. Women’s experiences were complex and the issues of having CDPP continued well beyond pregnancy and the first year postpartum.

Sixth, this research provides unique data on the types and features of resources and support preferred by women with CDPP. This information can be used to guide further research and the development of resources and programs which ultimately improves outcomes for women. The top three support options identified in the needs assessment (peer support, counselling, and access to a cardiac link nurse) directly address the key concerns identified in the qualitative interviews and qualitative survey, that is, mental health, isolation, knowledge, and services that are responsive to their unique needs as mothers with cardiac conditions.

This thesis has provided a voice for women with CDPP. It contributes to the knowledge base on the experiences and needs of women who have CDPP, providing a platform for health service improvement. The finding of this research can be adopted and developed in a range of clinical specialities and across disciplines. This thesis also outlines recommendations for future research and pilot projects as well as for the health care system broadly and healthcare professionals, and in doing so has identified multiple opportunities to improve the experiences and outcomes for women with CDPP.

Appendices

Appendix 1: Study 1 Participant characteristics

		Frequency	Percent
Age cardiac disease diagnosed (years)	0-5	7	28.0
	6-18	1	4.0
	19-30	5	20.0
	31-36	12	48.0
Age of first CDPP (years)	Missing	1	4.0
	Up to 25	1	4.0
	26 – 30	10	40.0
	31 - 36	6	24.0
	37 or older	7	28.0
Pregnancy for first CDPP	1st pregnancy	18	72.0
	2nd pregnancy	3	12.0
	3rd or later pregnancy	4	16.0
Number of pregnancies with CDPP	One	19	76.0
	Two	5	20.0
	Three or more	1	4.0
Timing of diagnosis	Before pregnancy	11	44.0
	During pregnancy	2	8.0
	Postpartum	12	44.0
Category of cardiac disease	Acquired	12	48.0
	Congenital	9	36.0
	Genetic	4	16.0
Education	School certificate (year 10)	3	12.0
	Trade qualification	7	28.0
	Tertiary qualification	15	60.0
Occupation	Hospitality	1	4.0
	IT	1	4.0
	Creative arts	2	8.0
	Clerical and administration	2	8.0
	Community/personal support workers	2	8.0
	Manager	4	16.0
	Professional	13	52.0

Mean age at time of interview 39 years (range 28 to 59 years)

Study 1 Participant diagnoses

Acquired

- Idiopathic cardiomyopathy
- Peripartum cardiomyopathy (PPCM)
- Pregnancy related spontaneous coronary artery dissection (PSCAD)

Congenital

- Bicuspid Aortic Valve
- Left Ventricular Non-Compaction Syndrome
- Mitral Valve Prolapse
- Patent Ductus Arteriosus
- Patent Foramen Ovale
- Tetralogy of Fallot

Genetic

- Arrhythmogenic Right Ventricular Dysplasia/Cardiomyopathy
- Hypertrophic Cardiomyopathy
- Long QT Syndrome

Appendix 2: Study 1 Interview guide

Health care experiences among first time mothers with pre-existing or newly diagnosed cardiac disease - Interview guide

Consent

1. Check that consent has been received. If no written consent has been received, seek oral consent.
2. Remind the participant that the aim of the research is to learn about the health care experiences of mothers who have an existing or new diagnosis of cardiac disease.
3. Answer any questions arising from the participant information.
4. Ask permission to record the interview.

Demographic information

Place of residence	metropolitan	regional	Rural/remote	
Relationship status during pregnancy	married/defacto	single	divorced/separated	
Relationship status now	married/defacto	single	divorced/separated	
Level of education	primary school	secondary school	trade certificate	tertiary
Occupation				
Age now				
Age at diagnosis				
Year of diagnosis				
Pre-existing diagnosis	yes	No		
If yes – age of diagnosis				
If no – gestation at diagnosis				
Diagnosis/condition				
How was your cardiac condition first detected	As a baby - neonatologist	GP	Obstetrician	Other (specify)
Private or public obstetric services	Private	Public		
Private or public cardiologist	Private	public		a/a
Number of pregnancies				
Birth outcome	Live birth	Stillbirth		
Gestation				
Mode of birth	Vaginal	Assisted vaginal	LSCS	

Focal story (Let participant tell her story without asking direct questions)

E.g., *"Can you tell me about your experience [of having cardiac disease during pregnancy or after the birth of your baby]?"*

Experience of health care (unless covered in focal story ask about)

Views about care at the time of and after the diagnosis, whether this met their needs, what worked and what did not work and how things could be improved in terms of:

- What was the interaction between your doctors, midwives and any other healthcare professionals like?
- How would you rate the quality of the information you were given?
- How consistent was the information you were given from different people (and was there any conflict in advice/information between health care professionals)?
- Do you feel that you received emotional/psychological support about having a cardiac condition and being a first time mother? Was it helpful? (If not already specified; Who provided support?)
- Did your health care providers include your partner or family/friend in consultations?
- What follow-up cardiac care was arranged?
- Did you receive any advice or recommendations about choice of contraception?
- Did you receive any advice regarding future pregnancies, including pregnancy spacing?
- Did you have a natural conception or was it with assisted reproductive technology?

We are thinking about setting up a long-term study that will follow women and their babies into the future to observe things like ongoing health and wellbeing:

- What do you think about this?
- What sort of things do you think we should look at?

Appendix 3: Study 2 Participant characteristics

		Frequency	Percent
Age cardiac disease diagnosed (years)	0-5	9	20.9
	6-18	1	2.3
	19-30	13	30.3
	31 years and older	20	46.5
Age of first CDPP	missing	2	4.7
	18-25	3	7.0
	26-30	18	41.9
	31-36	12	27.9
	37-42	8	18.6
Number of pregnancies with CDPP	One	30	69.8
	Two	6	13.9
	Three or more	7	16.3
Pregnancy for first CDPP	1st pregnancy	30	69.8
	2nd pregnancy	7	16.3
	3rd pregnancy	4	9.3
	4th pregnancy	1	2.3
	5th or later pregnancy	1	2.3
Timing of diagnosis	Before pregnancy	14	32.6
	During pregnancy	6	14.0
	Postpartum	23	53.4
Year of first CDPP	Missing	1	2.3
	2005-2010	9	20.9
	2011-2016	10	23.3
	2017-2021	23	53.5
Category of cardiac disease	Acquired	25	58.1
	Congenital	11	25.6
	Genetic	7	16.3

Study 2 participant diagnosis

Diagnoses

Several women had multiple conditions, diagnosed simultaneously or at separate times.

Acquired

- Idiopathic cardiomyopathy
- Peripartum cardiomyopathy

- Pregnancy related spontaneous coronary artery dissection

Congenital

- Arrhythmogenic mitral valve prolapse
- Atrial septal defect
- Coarctation and stenosis of the aorta
- Congenitally corrected transposition of the great arteries
- Dextrocardia
- Fontan circulation
- Leaky valve
- Pulmonary stenosis
- Transposition of the great vessels
- Tetralogy of Fallot
- Transposition of great arteries
- Ventricular septal defect

Genetic

- Arrhythmogenic Right Ventricular Dysplasia/Cardiomyopathy
- Long QT Syndrome
- Supraventricular tachycardia

Appendix 4: Study 2 Online survey

Quality of life following cardiac disease in pregnancy and the first 12 months postpartum.

You have been invited to participate because you have experienced cardiac disease whilst pregnant or in the first 12 months postpartum; *you may have been diagnosed with cardiac disease any time prior to pregnancy, during pregnancy or in the first 12 months postpartum but are not pregnant now*.

Part A: Inclusion criteria

1. Within the last 10 years, have you had cardiac disease during pregnancy or in the first 12 months after giving birth? (You may have had a pre-existing condition or newly diagnosed condition.)
   a) No – exit study
   b) Yes – continue

2. For your pregnancy with cardiac disease, did give birth to one or multiple babies beyond 20 weeks gestation or 400gm or greater birthweight?
   a) No – exit study
   b) Yes – continue

3. Was your diagnosis hypertension or preeclampsia?
   a) No – continue
   b) Yes – exit study

4. Are you currently living in Australia and were you living in Australia at the time of your cardiac disease in pregnancy or the first year postpartum?
   a) No – exit study
   b) Yes – continue

5. Are you 18 years of age or older?
   a) No – exit study
   b) Yes– continue

*Exit answers: Thank you for offering to complete the survey; unfortunately you do not meet the inclusion criteria this time.

Part B: Cardiac disease

6. What age were you first diagnosed
   a) 0-5 years
   b) 6-18 years
   c) 19-30 years
   d) 31 years and over

7. What is your primary (main) cardiac diagnosis? ___________________________________

8. Were you diagnosed?
   a) before pregnancy (including in infancy and childhood)?
   b) during pregnancy
   c) in the first 12 months postpartum

9. Did you have cardiac disease in pregnancy or postpartum **for the first time** with your
   a) 1st pregnancy

b) 2nd pregnancy
c) 3rd pregnancy
d) 4th pregnancy
e) 5th or later pregnancy

10. What year did you have cardiac disease in pregnancy or postpartum for the first time?

11. How old were you when you have cardiac disease in pregnancy or postpartum for the first time?

Part C: General quality of life

The questions are from the World Health Organization Quality of Life (Brief) Survey and they ask how you feel about your quality of life or other areas of your life. Please answer all questions. If you are unsure of which answer to give, please choose the one that appears most appropriate, or closest to what feels right. This is often your first response.

Please keep in mind your standards, hopes, please and concerns when answering the questions. For all questions in this section please answer as it applies for your life in the ***last 2 weeks***.

12	How would you rate your quality of life?	very poor	poor	neither good nor poor	good	very good
13	How satisfied are you with your health?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied

The following questions ask about how much you have experienced certain things in the ***last two weeks.***

14	To what extent do you feel that physical pain prevents you from doing what you need to do?	not at all	a little	a moderate amount	very much	an extreme amount
15	How much do you need any medical treatment to function in your daily life?	not at all	a little	a moderate amount	very much	an extreme amount
16	How much do you enjoy life?	not at all	a little	a moderate amount	very much	an extreme amount
17	To what extent do you feel your life to be meaningful?	not at all	a little	a moderate amount	very much	an extreme amount
18	How well are you able to concentrate?	not at all	a little	a moderate amount	very much	extremely
19	How safe do you feel in your daily life?	not at all	a little	a moderate amount	very much	extremely
20	How healthy is your physical environment?	not at all	a little	a moderate amount	very much	extremely

The following questions ask about how completely you experience or were able to do certain things in the ***last two weeks****.*

21	Do you have enough energy for everyday life?	not at all	a little	moderately	mostly	completely
22	Are you able to accept your bodily appearance?	not at all	a little	moderately	mostly	completely
23	Have you enough money to meet your needs?	not at all	a little	moderately	mostly	completely
24	How available to you is the information that you need in your day-to-day life?	not at all	a little	moderately	mostly	completely
25	To what extent do you have the opportunity for leisure activities?	not at all	a little	moderately	mostly	completely

26	How well are you able to get around?	very poor	poor	neither	well	very well

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over ***the last two weeks.***

27	How satisfied are you with your sleep?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
28	How satisfied are you with your ability to perform your daily living activities?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
29	How satisfied are you with your capacity for work?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
30	How satisfied are you with yourself?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
31	How satisfied are you with your personal relationships?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
32	How satisfied are you with your sex life?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
33	How satisfied are you with the support you get from your friends?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
34	How satisfied are you with the conditions of your living place?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
35	How satisfied are you with your access to health services?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied
36	How satisfied are you with your transport?	very dissatisfied	dissatisfied	neither satisfied nor dissatisfied	satisfied	very satisfied

The following question refers to how often you have felt or experienced certain things in the ***last two weeks****.*

37	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	never	seldom	quite often	very often	always

Part D: Quality of life for women with cardiac disease

This section is specifically about your experiences with cardiac disease. Please choose the answer that appears most appropriate or closest to your experience; this is often your first response. Some questions require a written answer.

38	Please indicate how much you are limited by cardiac symptoms (e.g. shortness of breath, chest pain, fatigue, palpitations or other) in your ability to do the following activities **over the past 2 weeks.**						
a)	Walking 1 block on level ground	Extremely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Limited for other reasons or did not do the activity
b)	Doing yard work, housework, carrying groceries	Extremely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Limited for other reasons or did not do the activity

c)	Climbing a flight of stairs without stopping	Extremely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Limited for other reasons or did not do the activity
d)	Hurrying or jogging (eg to catch a bus)	Extremely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Limited for other reasons or did not do the activity

39	How many years/months ago were you diagnosed with your cardiac condition (i.e., diagnosed, not when you were pregnant or postpartum)	Year(s)	Month(s)

40	How did you feel when told about the diagnosis or were old enough to understand, (tick all that apply)	Depressed	Hopeless	Did not feel anything	Confused	Desperate	Anxious	fearful / scared	felt that everything will ok in the end	Disappointed	other

41	Do you think that you received adequate information and counselling regarding your diagnosis from your health care providers?	Yes, absolutely	Yes, but had questions which remained unanswered	No	Do not know	Other (add)
42	Was the information and advice given clear and easy to understand?	Very clear	Fairly clear	Could be clearer	Unclear	I received no advice

43	How well do you understand what things you are able to do to help manage your cardiac condition? (e.g. diet, exercise)	Do not understand at all	Do not understand very well	Somewhat understand	Mostly understand	Completely understand

44	When did you feel that you achieved your baseline level of activity after pregnancy if diagnosed before or during pregnancy *Or* After your cardiac diagnosis if diagnosed postpartum	Immediately, as soon as I received treatment I was back to baseline	Immediately after I gave birth	1 week after I gave birth or diagnosed and started treatment	1 month after I gave birth or diagnosed and started treatment	6 months after I delivered or diagnosed and started treatment	I never returned to baseline	Other (add)
45	When did you feel that emotionally you returned back to your normal baseline?	I was never emotionaly devastated	Soon after my diagnosis	__ weeks	__ months	__ years	Never returned to baseline	Other (add)

46	Do you recall being told or advised to avoid future pregnancies?	Yes	No	I can't recall

47	If you were advised to avoid future pregnancies, was a referral for counselling & support offered?	Yes, and I took it up	Yes, and I didn't take it up	No, and I had none	No, but I sought it out myself	Can't recall
48	What was it like to be told to not have more children?	Devastating	Hard, still really upsets me	Upsetting, but I got over it quickly	A bit upsetting	Not an issue

The following questions refer to the ***past 2 weeks***.

49	Compared with 2 weeks ago, have your cardiac symptoms (e.g. shortness of breath, fatigue or chest pain) changed?	Much worse	Slightly worse	Not changed	Slightly better	Much better	I have had no symptoms over last 2 weeks
50	Over the past 2 weeks, how much have your cardiac symptoms bothered you?	Extremely bothersome	Quite a bit bothersome	Moderately bothersome	Slightly bothersome	Not at all bothersome	I have had no symptoms over last 2 weeks

51	Over the past 2 weeks, on average, how many times has fatigue limited your ability to do what you want?	All the time	Several times per day	At least once a day	3 or more times per week but not every day	1-2 times per week	Less than once per week	Never over the past 2 weeks
52	Over the past 2 weeks, on average, how many times has shortness of breath limited your ability to do what you want?	All the time	Several times per day	At least once a day	3 or more times per week but not every day	1-2 times per week	Less than once per week	Never over the past 2 weeks
53	Over the past 2 weeks, on average, how many times has chest pain limited your ability to do what you want?	All the time	Several times per day	At least once a day	3 or more times per week but not every day	1-2 times per week	Less than once per week	Never over the past 2 weeks

54	If you had to spend the rest of your life with your cardiac condition the way it is right now, how would you feel about this?	Not at all satisfied	Mostly dissatisfied	Somewhat satisfied	Mostly satisfied	Completely satisfied
55	Over the past 2 weeks, how often have you felt discouraged or down in the dumps because of your cardiac condition?	I felt that way all of the time	I felt that way most of the time	I occasionally felt that way	I rarely felt that way	I never felt that way

56	How much does your cardiac condition affect your lifestyle? Please indicate how your cardiac condition may have limited your participation in the following activities over the ***past 2 weeks.***						
a)	Hobbies, recreational activities	Severely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Does not apply or did not do for other reasons
b)	Caring for your children or other family members	Severely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Does not apply or did not do for other reasons
c)	Working/paid employment/volunteering	Severely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Does not apply or did not do for other reasons
d)	Doing household chores	Severely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Does not apply or did not do for other reasons
e)	Visiting family or friends out of your home	Severely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Does not apply or did not do for other reasons
f)	Intimacy/sex	Severely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Does not apply or did

							not do for other reasons
g)	Exercising or playing sport	Severely Limited	Quite a bit Limited	Moderately Limited	Slightly Limited	Not at all Limited	Does not apply or did not do for other reasons

57	Are you concerned that sexual activity could be dangerous or unsafe for your heart?	Very concerned	Somewhat concerned	A little concerned	Not at all concerned	I'm not sexually active for other reasons

58	Has having your cardiac condition stopped you from taking holidays, or made you take different holidays?	Haven't taken a holiday since my diagnosis or pregnancy/post partum	Completely changed the destination, travel, duration or style of holiday	Moderately changed the destination, travel, duration or style of holiday	Changed the destination, travel, duration or style of holiday a little	No changes
59	Over the past 2 weeks, how much has your cardiac condition limited your enjoyment of life?	It has extremely limited my enjoyment of life	It has limited my enjoyment of life quite a bit	It has moderately limited my enjoyment of life	It has slightly limited my enjoyment of life	It has not limited my enjoyment of life at all

60	Have you been unable to follow diet and exercise recommendations because of mothering responsibilities?	Almost always	Most of the time	Sometimes	Hardly ever	Never	I wasn't given any recommend-ations

60	Have you missed medical appointments due to difficulty arranging childcare?	Almost always	Most of the time	Sometimes	Hardly ever	Never
61	Have you missed medical appointments due to the cost?	Once	Twice	Three times or more	Never, it is free or low cost	Never, I pay the regular fee

63	Did you discontinue or reduce work because of your cardiac condition	Yes, I stopped working	Yes, I had to reduce my hours or change role	No	Not applicable (wasn't working)

64	Are you concerned about the financial impact of living with a cardiac condition?	Very concerned	Somewhat concerned	A little concerned	Not at all concerned
65	Do you worry that your child/children will develop a cardiac condition?	Very concerned	Somewhat concerned	A little concerned	Not at all concerned
66	Are you concerned that you will not live as long because of your cardiac condition?	Very concerned	Somewhat concerned	A little concerned	Not at all concerned

This next section asks about any symptoms or anxiety or worry you may experience about your heart health. Please rate each item choosing the answer that best applies to you ***now***.

67	I pay attention to my heart beat	never	rarely	sometimes	often	always
68	I avoid physical exertion	never	rarely	sometimes	often	always
69	My racing heart wakes me up at night	never	rarely	sometimes	often	always

70	Chest pain/discomfort wakes me up at night	never	rarely	sometimes	often	always
71	I take it easy as much as possible	never	rarely	sometimes	often	always
72	I check my pulse	never	rarely	sometimes	often	always
73	I avoid exercise or other physical work	never	rarely	sometimes	often	always
74	I can feel my heart in my chest	never	rarely	sometimes	often	always
75	I avoid activities that make my heart beat faster	never	rarely	sometimes	often	always
76	If tests come out normal, I still worry about my heart	never	rarely	sometimes	often	always
77	I feel safe being around a hospital, physician or other medical facility	never	rarely	sometimes	often	always
78	I avoid activities that make me sweat	never	rarely	sometimes	often	always
79	I worry that doctors do not believe my symptoms are real	never	rarely	sometimes	often	always

When I have chest discomfort or when my heart is beating fast:

80	I worry that I may have a heart attack	never	rarely	sometimes	often	always
81	I have difficulty concentrating on anything else	never	rarely	sometimes	often	always
82	I get frightened	never	rarely	sometimes	often	always
83	I like to be checked out by a doctor	never	rarely	sometimes	often	always
84	I tell my family or friends	never	rarely	sometimes	often	always

Please consult with your GP or cardiologist if you have concerns or questions about your cardiac health or any symptoms you may be experiencing.

Part E: Emotional wellbeing

Please read each statement and select the answer that most closely reflects how much the statement applied to you over the ***past week.*** There are no right or wrong answers. Do not spend too much time on any statement; you're first response is usually to right one.

If you select the third column, "*Applied to me to a considerable degree, or a good part of time*" for more than half your answers, or any of the fourth column "*Applied to me very much, or most of the time*", or if you feel any distress completing this section we recommend that you discuss this with your GP or psychologist or counsellor. Contact details and referral options are listed at the end of this section.

85	I found it hard to wind down	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
86	I was aware of dryness of my mouth	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
87	I couldn't seem to experience any positive feeling at all	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
88	I experienced breathing difficulty (in the absence of physical exertion)	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
89	I found it difficult to work up the initiative to do things	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
90	I tended to over-react to situations	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
91	I experienced trembling (eg, in the hands)	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time

92	I felt that I was using a lot of nervous energy	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
93	I was worried about situations in which I might panic and make a fool of myself	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
94	I felt that I had nothing to look forward to	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
95	I found myself getting agitated	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
96	I found it difficult to relax	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
97	I felt down-hearted and blue	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
98	I was intolerant of anything that kept me from getting on with what I was doing	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
99	I felt I was close to panic	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
100	I was unable to become enthusiastic about anything	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
101	I felt I wasn't worth much as a person	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
102	I felt that I was rather touchy	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
103	I was aware of the action of my heart in the absence of physical exertion	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
104	I felt scared without any good reason	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time
105	I felt that life was meaningless	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree, or a good part of time	Applied to me very much, or most of the time

If you feel distressed about your experiences or health, please consider contacting one of the following:

- If distress is related to anxiety about potential maternal or birth outcomes: Perinatal Anxiety & Depression Australia (PANDA) National Helpline is free and available Monday to Friday, 9am - 7.30pm AEST) 1300 726 306 or email support@panda.org.au and information is available on their website https://www.panda.org.au/. PANDA provides a safe and confidential space for any new or expecting parent struggling with the challenges of becoming a new parent.

- If distress is related to a miscarriage, stillbirth or neonatal death: the SANDS helpline is available 24 hours a day, 365 days a year on 1300 072 637 plus they provide email, Live Chat & Facebook groups, https://www.sands.org.au/

- For 24 hours mental health support: Lifeline provides 24 hours mental health support via phone on 13 11 14, online chat https://www.lifeline.org.au/crisis-chat/ or text https://www.lifeline.org.au/crisis-text/ 0477 13 11 14. https://www.lifeline.org.au/

- Support is also available through Beyond Blue counselling 130022 4636 or online chat at https://www.beyondblue.org.au.

- Your GP, cardiologist or obstetrician may also be available for support and they can refer you for Medicare subsidised counselling if required.

- If you would like further information please contact the research team: Jane Hutchens, PhD student: Jane.Hutchens@student.uts.edu.au, Dr Jane Frawley, supervisor: jane.frawley@uts.edu.au

Part F: Experiences of mothering with a cardiac condition

Q 106 This section is about your experiences and quality of life as a mother with a cardiac condition, so please answer it from that perspective (i.e., **how having a cardiac condition impacts on your experiences of being a mother**).

Step 1 – identifying areas		**Step 2 – scoring areas**	**Step 3 – allocating points**
We would like you to think about the **most important** areas of your life that have been affected by having a baby as a woman with a cardiac condition. These can be **positive**, **negative**, or perhaps **both** or **neither** really one or the other. Please write up to 8 areas in the boxes below and indicate if it is positive, negative, both, or neither.		Now please score the areas you mentioned in Step 1. This score should reflect **how you have been affected** by this area has been for you over the **past month.** Please score from 0 to 10 **0 is the worst** – you couldn't feel any worse than this **10 is the best** – you couldn't feel any better than this	Think about how important these areas are to your quality of life. You have a total of 20 points to allocate. You don't have to allocate points to an area/item if you don't want to. Give more points to the areas that are most important to you. Your points must add up to 20.
Examples women have given in similar research: • How they feel about themselves • How they feel about their baby • How they feel about their relationship with their partner • Physical issues • Emotional issues • How they feel about socialising These are only examples, please say **what you feel** are the most important areas.	Please select if this point is Positive, Negative, Both/ Neither		
1	Positive, Negative, Both/ Neither		
2	Positive, Negative, Both/ Neither		
3	Positive, Negative, Both/ Neither		
4	Positive, Negative, Both/ Neither		
5	Positive, Negative, Both/ Neither		
6	Positive, Negative, Both/ Neither		
7	Positive, Negative, Both/ Neither		
8	Positive, Negative, Both/ Neither		
		Total	20

Part G: Resources and support

Q 107 Thinking back to when you were *pregnant or in the first year postpartum* with cardiac disease, how helpful do you think the following would have been?					
	Not at all useful	Somewh at useful	Useful	Very useful	Extremely useful
A cardiac nurse who you could call to provide information, referral options and support					
A dedicated website (or page on a broader cardiac website) for your cardiac condition					
A dedicated website (or page on a broader cardiac website)for your cardiac condition during pregnancy or postpartum					
A public Facebook page for your cardiac condition (or category of cardiac disease)					
A private Facebook group for your cardiac condition (or category of cardiac disease)					
Printed material about your condition					
Printed material with tips to manage your health and wellbeing					
For an appointment with a counsellor to be part of standard care					
Being able to speak with another woman who had a similar/same condition during pregnant or postpartum					
Other – rate					
Other – describe					

Part H: A little bit about you

110. Please indicate your age
    a) 19-25
    b) 26-30
    c) 31-36
    d) 37-42
    e) 43-48
    f) 49 and over

111. What is the highest education qualification you have gained?
    a) Year 10 (School Certificate or equivalent) or lower
    b) Year 12 (Higher School Certificate or equivalent)
    c) Trade/apprenticeship/certificate/diploma
    d) Undergraduate degree (bachelor degree)
    e) Postgraduate degree (honours degree, graduate certificate, graduate diploma, master degree, doctorate)

112. Do you currently have a health care card due to your cardiac condition?
    This is a card that entitles you to discounts and assistance with medical expenses. This is not the same as a Medicare care. (*Mark one only*)
    a) Yes
    b) No

113. How do you manage on the income you have available? (Mark one only)

a) It is impossible
b) It is difficult all of the time
c) It is difficult some of the time
d) It is not too bad
e) It is easy

114. What is your present marital status?
a) Never married
b) Married
c) Defacto
d) Separated
e) Divorced
f) Widowed

115. Which state or territory do you currently live in?
a) New South Wales
b) Australian Capital Territory
c) Queensland
d) Victoria
e) South Australia
f) Tasmania
g) Northern Territory
h) Western Australia

116. Please indicate how many children you have in the following categories. (Mark all that apply)
a) Younger than 6 months ___
b) 6months < 1 year ___
c) Aged 1 ___
d) Aged 2 ___
e) Aged 3 ___
f) Aged 4 ___
g) Aged 5 or over ___

Part I: Next steps - Focus group

The next step in our research is to develop recommendations for government and non-government organisations and health professionals on strategies to improve support and resources for women who have cardiac disease in pregnancy and the first 12 months postpartum. To develop the strategies we will use these results from this study plus focus groups (separate groups for women and health professionals).

In the focus group we will discuss possible options and gather ideas and feedback in an informal online forum (e.g. using Zoom or other platform). If you're interested in being part of the focus group please click here <link> to provide your contact details and we will be in contact with more information. *Please note*, this link takes you to a separate page and it is not linked to the survey, so your survey answers remain anonymous.

Thank you very much for your participation. We have asked you *a lot* of questions and we appreciate your time and generosity in being part of the study.

Appendix 5: Study 3 Participant diagnoses

Acquired
- Idiopathic cardiomyopathy
- Peripartum cardiomyopathy
- Pregnancy related spontaneous coronary artery dissection

Congenital
- Fontan circulation
- Tetralogy of Fallot

Genetic
- Arrhythmogenic Right Ventricular Dysplasia/Cardiomyopathy
- Long QT Syndrome

Appendix 6: Focus group guide

ETH21-6641 needs assessment: cardiac disease in pregnancy and the first 12 months postpartum

Focus group outline

Note: the group will be semi-structured and questions will be adapted in response to the discussion. Not all of the following questions will be asked, this list is indicative not prescriptive.

Introduction

1. Welcome and thank participants for joining.
2. Introduce myself, Jane and Liz.
3. *Set up the session*:
   - Explain we are seeking their opinions and thoughts about what services, resources, support may be useful for women with cardiac disease in pregnancy and the first year postpartum, and ongoing.
   - Note that there are no right or wrong opinions and that we are seeking all perspectives.
   - Briefly review the results of the needs assessment question in the survey.
   - Remind them that they have different diagnoses and timing of diagnoses, thus different experiences and so will likely have different suggestions, and that all are valid and sought.
   - Clarify that we are not talking about their experiences, rather we are discussing what resources and support could be provided and we are building on the data from the survey they completed.
4. Group introductions
5. Group rules
   - Confidentiality of the group
   - respect for people experiences and opinions
   - Remind them they can chose to not be involved in any discussion they choose not to, can seek to speak with one of the facilitators in a zoom breakout room and can leave the group at any point.

Questions/prompts

The survey results in order of ranking, with the focus today on the top 3

1. *Peer connection*
2. *Counselling*
3. *Cardiac link nurse*
4. Website specifically about cardiac disease in pregnancy and postpartum
5. Website of their diagnosis/condition
6. Private Facebook group for the condition
7. Printed information on their condition
8. Public Facebook page for their condition
9. Printed information on health tips for their conditions

Peer support

What would peer support look like?

- For the peer support volunteer, how important is
    - exact diagnosis, time since they had their child, their age, their location?
- When would you want to first meet?
- How many times/how long would you want to meet?
- If you had a peer when you were going through pregnancy/postpartum with heart disease, what would you have wanted her to tell you?
- What qualities should they have?
- Who do you think should run the peer support service?
- If you were a peer, what do you think the most important things are that you could share with another woman?
- What would stop you from becoming a peer support vollie- and – encourage you to be a peer support vollie?
- What are the most important things a peer provides - information (disease, health professional referral options, mothering etc), connection with like person, re-assurance?
- Would group peer support be good? Pros & cons
- Would one-on-one peer support be good?
- Pros & cons

Counselling

What would a counselling program or service involve?

- Thinking about the counsellor/psychologist, what specialised education and experience do you think would be most helpful - cardiac, chronic health, women's health general, perinatal mental health, trauma? (That is, hat aspect is most important to them)
- When are the touch points for meeting - eg. at time of diagnosis, puberty, preconception, pregnancy, postpartum, 6 or 12 months after pregnancy or postpartum heart event?
- How many sessions do you think would be good to have as a starting point? (Context – if a set number of appointments was included in routine care)
- What qualities should they have?
- Who do you think should provide the counselling - hospital, heart organisations, mental health organisations, private?
- Would group support be helpful (i.e. with other women with heart disease in pregnancy and postpartum and a counsellor)?
- What do you think about stress reduction strategies help? For example, the Mindfulness Stress Reduction Program?

Cardiac link nurse

What role would they play?

- If you had a cardiac link nurse you could have called when you were pregnant with a heart condition, or when you had a cardiac event postpartum, what sorts of things would you have asked them, or used them for?
- Should they be attached to/employed by a uni, a hospital or area health service, a clinical research institute (e.g Baker Heart Foundation, Centenary Institute, Victor Chang) or someone like the Heart Foundation?
- What should they know?
- What should they be like? What qualities do you think would be helpful?
- How often do you think you would have called them?
- Would you use them now even if your pregnancy or heart event was a few years or more ago?
- What are the most important things a cardiac link nurse provides – information (disease, health professional referral options, mothering etc), connection and continuity, re-assurance?

Closing questions

- What have we missed?
- Any last thoughts or comments?
- Why did you decide to join this focus group?

Wrap up

- Thank for their participation.
- Reiterate the value of their input and the research.
- Remind them I will email a draft summary of the findings within 4 weeks and ask for their feedback.
- Let them know if they have any questions or concerns that they can phone or email me.

Appendix 7: Ethics approvals

On 22/3/19, 12:58 pm, "Research.Ethics@uts.edu.au" <Research.Ethics@uts.edu.au> wrote:

Dear Applicant

UTS HREC REF NO. ETH19-3372

The UTS Human Research Ethics Expedited Review Committee reviewed your amendment application for your project titled, "Health care experiences of mothers with pre-existing or newly diagnosed cardiac disease", and agreed that the amendments meet the requirements of the NHMRC National Statement on Ethical Conduct In Human Research (2007). I am pleased to inform you that the Committee has approved your request to amend the protocol as follows:

"We would like to interview women who have had cardiac disease in any pregnancy (as opposed to just first pregnancies)."

This amendment is subject to the standard conditions outlined in your original letter of approval.
You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (http://www.gsu.uts.edu.au/policies/research-management-policy.html).

You should consider this your official letter of approval. If you require a hardcopy please contact the Research Ethics Officer (Research.Ethics@uts.edu.au).

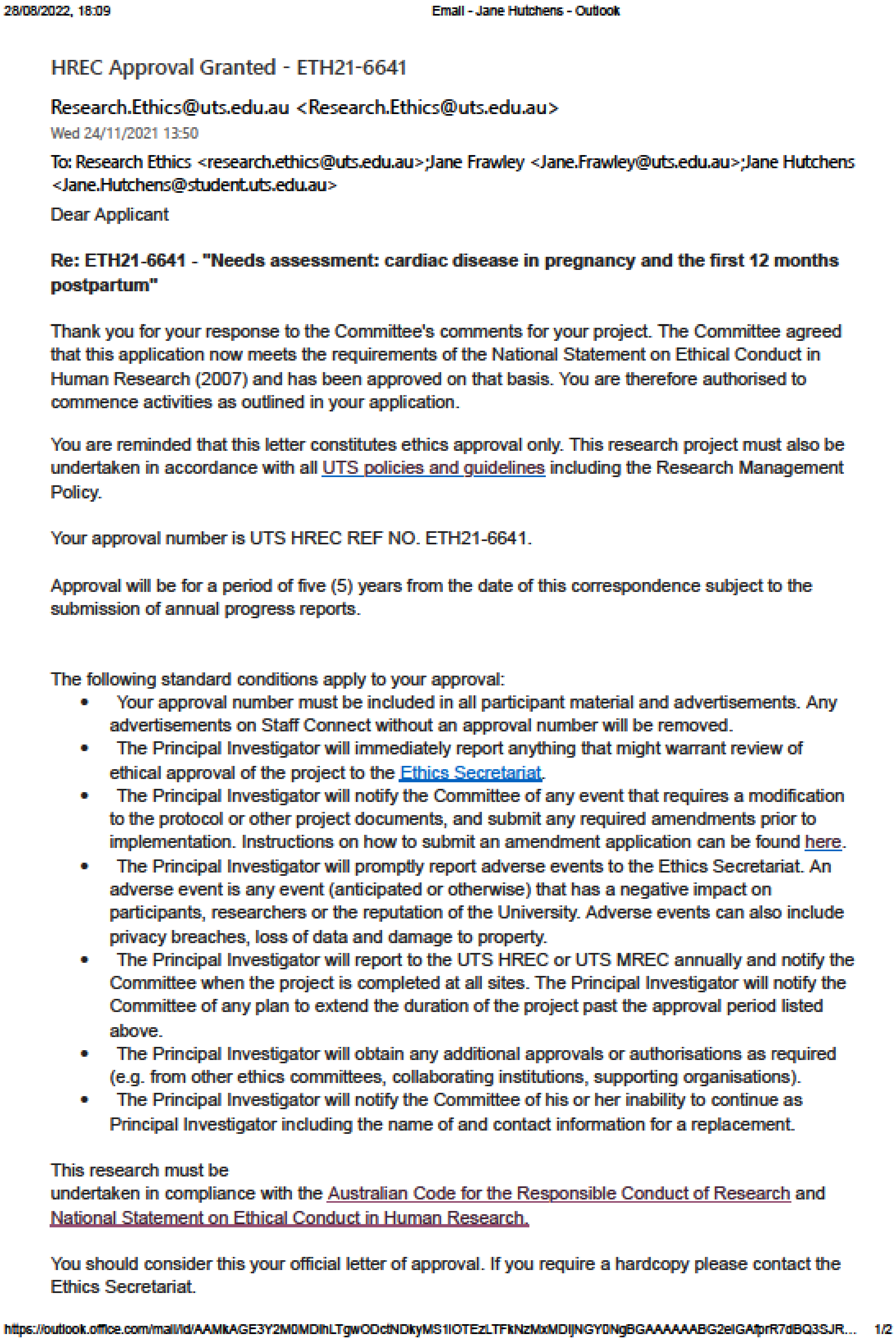
To access this application, please follow the URLs below:
* if accessing within the UTS network: https://rm.uts.edu.au
* if accessing outside of UTS network: https://vpn.uts.edu.au , and click on " RM6 – Production " after logging in.

If you wish to make any further changes to your research, please contact the Research Ethics Secretariat in the Research and Innovation Office on 02 9514 2478.

In the meantime I take this opportunity to wish you well with the remainder of your research.

Yours sincerely,

A/Prof Beata Bajorek
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology, Sydney



HREC Approval Granted - ETH21-6641

Research.Ethics@uts.edu.au <Research.Ethics@uts.edu.au>
Wed 24/11/2021 13:50
To: Research Ethics <research.ethics@uts.edu.au>;Jane Frawley <Jane.Frawley@uts.edu.au>;Jane Hutchens <Jane.Hutchens@student.uts.edu.au>

Dear Applicant

Re: ETH21-6641 - "Needs assessment: cardiac disease in pregnancy and the first 12 months postpartum"

Thank you for your response to the Committee's comments for your project. The Committee agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application.

You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy.

Your approval number is UTS HREC REF NO. ETH21-6641.

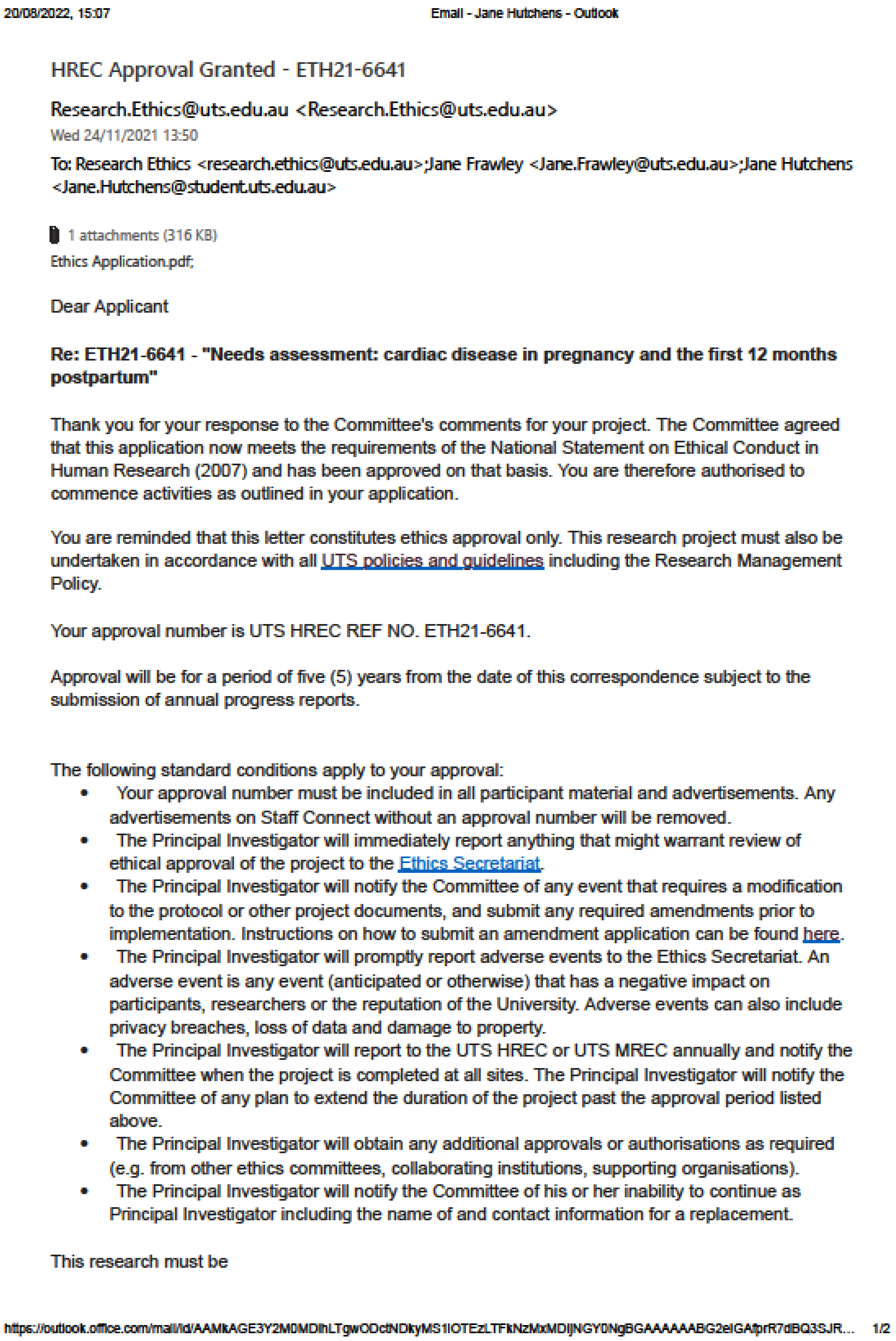
Approval will be for a period of five (5) years from the date of this correspondence subject to the submission of annual progress reports.

The following standard conditions apply to your approval:

- Your approval number must be included in all participant material and advertisements. Any advertisements on Staff Connect without an approval number will be removed.
- The Principal Investigator will immediately report anything that might warrant review of ethical approval of the project to the Ethics Secretariat.
- The Principal Investigator will notify the Committee of any event that requires a modification to the protocol or other project documents, and submit any required amendments prior to implementation. Instructions on how to submit an amendment application can be found here.
- The Principal Investigator will promptly report adverse events to the Ethics Secretariat. An adverse event is any event (anticipated or otherwise) that has a negative impact on participants, researchers or the reputation of the University. Adverse events can also include privacy breaches, loss of data and damage to property.
- The Principal Investigator will report to the UTS HREC or UTS MREC annually and notify the Committee when the project is completed at all sites. The Principal Investigator will notify the Committee of any plan to extend the duration of the project past the approval period listed above.
- The Principal Investigator will obtain any additional approvals or authorisations as required (e.g. from other ethics committees, collaborating institutions, supporting organisations).
- The Principal Investigator will notify the Committee of his or her inability to continue as Principal Investigator including the name of and contact information for a replacement.

This research must be
undertaken in compliance with the Australian Code for the Responsible Conduct of Research and National Statement on Ethical Conduct in Human Research.

You should consider this your official letter of approval. If you require a hardcopy please contact the Ethics Secretariat.



HREC Approval Granted - ETH21-6641

Research.Ethics@uts.edu.au <Research.Ethics@uts.edu.au>

Wed 24/11/2021 13:50

To: Research Ethics <research.ethics@uts.edu.au>;Jane Frawley <Jane.Frawley@uts.edu.au>;Jane Hutchens <Jane.Hutchens@student.uts.edu.au>

1 attachments (316 KB)

Ethics Application.pdf;

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Thank you for your response to the Committee's comments for your project. The Committee agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application.

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- The Principal Investigator will obtain any additional approvals or authorisations as required (e.g. from other ethics committees, collaborating institutions, supporting organisations).
- The Principal Investigator will notify the Committee of his or her inability to continue as Principal Investigator including the name of and contact information for a replacement.

This research must be

Appendix 8: Heart Foundation report - The healthcare experiences of women with cardiac disease in pregnancy and postpartum

mother + heart

THE HEALTHCARE EXPERIENCES OF WOMEN WITH CARDIAC DISEASE IN PREGNANCY AND THE FIRST YEAR POSTPARTUM

Background

Cardiac disease in pregnancy and postpartum (CDPP) is pre-existing or newly diagnosed cardiac disease in pregnancy or in the first 12 months postpartum. CDPP includes a variety of structural heart and aortic diseases, cardiomyopathies, rhythm disorders, ischaemic heart disease, and arterial dissections, and excludes hypertension and preeclampsia.

CDPP is under-researched in Australia and internationally. Prevalence estimates range from 1% to 4%, equating to about 3-12,000 women in Australia affected per annum. There is evidence of increasing prevalence due to delayed childbearing, growing rates of lifestyle risk factors, and increasing rates of congenital heart disease survivors having children.

CDPP is a leading cause of maternal morbidity and is associated with significant serious maternal morbidity. There is a lack of data on affected women's healthcare experiences to inform health service delivery and person-centred care.

Methods

We conducted a qualitative study using in-depth semi-structured interviews with women who had CDPP. Participants were recruited from across Australia and interviews were conducted by phone. Data were analysed using thematic analysis.

Participants

Participants were 25 women with acquired (n=12), genetic (n=8) and congenital heart disease (n=5). Timing of diagnosis ranged from 3 days old to 11 months postpartum. Median age at interview was 39 years (range: 28-59). Most women lived in metropolitan areas, and of the four that lived in regional or rural areas, two transferred to metropolitan hospitals.

> “*I think overall there was just not enough assistance provided in relation to the fact that I'd just had a baby. That was my biggest takeaway. So, not enough education, not enough information, not enough reassurance, and not enough, like, options as to where to go next.*”

Findings

Analysis highlighted the discrepancy between care aspirations and experiences. The participants had a diversity of cardiac diseases and timing of diagnoses but had similar healthcare experiences of being dismissed, not receiving the information they required, lack of continuity of care and clinical guidelines, and of feeling out of place within a healthcare system that did not accommodate their combined needs as a mother and a cardiac patient. Five themes were developed as follows.

Themes

Dismissed: struggling to be heard

Feeling dismissed by healthcare professionals (HCPs) was the most dominant individual theme. It occurred in all settings, by all disciplines and was iterative. Being dismissed resulted in incorrect and delayed diagnoses, associated preventable morbidity and emotional distress, and a loss of trust in HCPs. When women were believed and acknowledged they felt safer and respected.

I could have just ended up dying in my bed and people would have still been saying "Oh, it's just the baby"

Too little, too much, too unclear: in search of information

Women sought information to understand their condition, inform decision-making, and to provide re-assurance and confidence They felt frustrated and concerned at the lack of information available and the way in which it was provided Some felt there was a perceived convention of withholding and gatekeeping information. When information was provided it was at times oversimplified or alternatively, medical terminology was used and not explained. They highly valuable being informed and being able to ask questions.

Winging it: research, education and guidelines

The answers I was getting weren't really based on research or on best guidelines or, experience

There was a perceived lack of research-informed clinical guidelines in cardiac, pregnancy and postpartum care and the women expressed frustration, disappointment and at times, apprehension about this. The absence of guidelines meant women and their healthcare providers spent additional time seeking information and guidance, often futilely. They reported a lack of clarity and consistency about their care and emphasised the need for more research and enhanced clinical training.

Fragments: care co-ordination and continuity

Women with CDPP were managed by HCPs from a range of disciplines and specialties; care co-ordination was inconsistent and was most often experienced as lacking by the women. Some women proactively sought to enhance care coordination and communication though this was usually unsuccessful. Lack of continuity of care resulted in mixed messages, compromised communication, fragmented disrupted care, and distress for women.

Making do: fitting into services designed for others

Women described being 'out of place' regardless of what ward they were in (cardiac, maternity, emergency or general wards) and that staff specialising in one area did not have knowledge of other aspects of her health. Outpatients and rehab did not accommodate mothers with babies, and rehab was designed for older people with different conditions. Mixed gender wards were particularly difficult for new mothers and ward management practices inconsistently reflected baby-friendly hospitals practices.

I was in a shared room with older men, a curtain between us, I'm there breast pumping, I've got my newborn there ... it was pretty horrendous

Conclusion and recommendations

This study found that the healthcare expectations and needs of women with CDPP were not being fully met. It is important to note that while most of the stories the women shared were of negative healthcare experiences, this does not imply that all of their healthcare experiences were negative. Some positive experiences were shared, particularly those highlighting the value to shared information and respectful communication.

Studies on women's healthcare experiences are essential to build patient agency, healthcare knowledge and inform care. This study identified a lack of PCC for women with CDPP. Of concern is that this equally applies across pre-existing and de novo diagnoses, reflecting a lack of responsiveness of the healthcare system to providing fit for purpose healthcare for women with complex chronic disease who are pregnant or new mothers.

It is recommended that further research includes examining the healthcare experiences and needs of diverse population groups. In particular, cardiac and maternity care providers have an opportunity to listen to women who are the experts on their emergent health care needs, contributing to development of the knowledge base on the healthcare experiences of having cardiac disease in pregnancy and postpartum.

This is a summary of the article *The healthcare experiences of women with cardiac disease in pregnancy and postpartum: a qualitative study* (under review) by J Hutchens, J Frawley and E Sullivan, funded by NSW Heart Foundation.

Appendix 9: Heart Foundation report – Voice & Self-advocacy of women with cardiac disease in pregnancy and postpartum

mother + heart

VOICE & SELF-ADVOCACY OF WOMEN WITH CARDIAC DISEASE IN PREGNANCY & THE FIRST YEAR POSTPARTUM

Background

Self-advocacy is being able to represent your interests within the health care decision-making process. The potential benefits of effective patient self-advocacy include improved person-centred care and quality of life, increased patient satisfaction, as well as reduced symptom burden and use of health services for preventable reasons.

Cardiac disease in pregnancy and the first year postpartum (CDPP) includes a range of genetic, congenital and acquired conditions, including structural heart and aortic disease, cardiomyopathies, rhythm disorders, ischaemic heart disease, and arterial dissections. Cardiac disease is a leading cause of maternal morbidity and mortality; international prevalence estimates for CDPP are 1% to 4% (which is approx. 3-12,000 women in Australia).

CDPP is time and context defined, however women have new or ongoing chronic cardiac disease and as their circumstances change they need to adjust and re-negotiate care and their daily lives. Women interact with a variety of healthcare professionals (HCPs) each with their own clinical focus, and they need to establish functional productive relationships with them all, often at times of acute cardiac events, deterioration and distress. It is important to understand women's experiences of self-advocating in this context to inform future education and support services. This analysis explored the contexts, impacts, barriers and women's responses to the barriers to self-advocacy.

Methods and data sources

We conducted a qualitative study using in-depth semi-structured interviews with women who had CDPP. Participants were recruited from across Australia and interviews were conducted by phone. Data were analysed using thematic analysis.

Participants

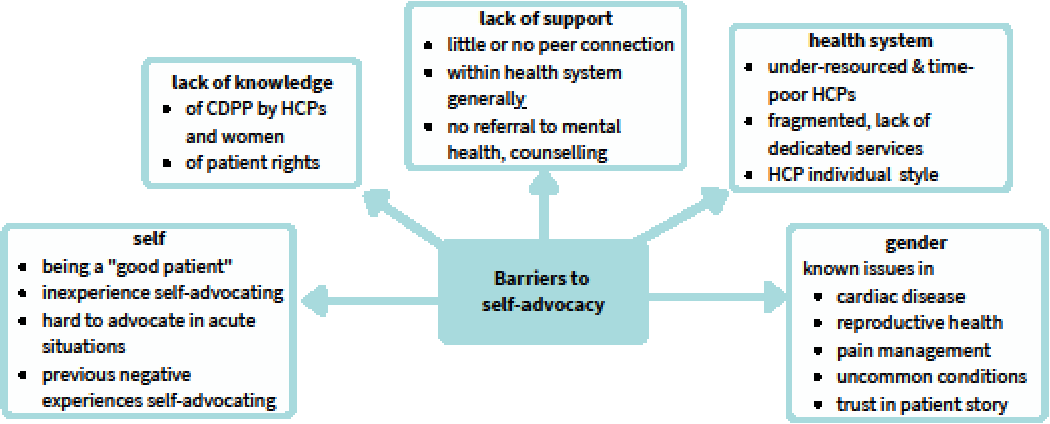
Participants were 25 women with acquired (n=12), genetic (n=8) and congenital heart disease (n=5). Timing of diagnosis ranged from 3 days old to 11 months postpartum. Median age at interview was 39 years (range: 28-59). Most women lived in metropolitan areas, and of the four that lived in regional or rural areas, two transferred to metropolitan hospitals.

Findings

Women's experiences were moderated by HCPs, the health system issues and gender. The complex and evolving relationship management required in promoting and protecting their physical and mental health places significant demands on women. Further, women with CDPP need to make informed decisions in an environment of little research, limited and at times conflicting information and guidance, and without the same level of organised support or access to peers as those with more common conditions.

Findings - themes

Silent dream scream Women were silent and silenced, especially at diagnosis, during labour and in childbirth. Feeling shocked, confused or fearful, some temporarily silenced themselves while they tried to regain their footing. They were silenced and dismissed by HCPs, some over many years, in ways significant to their physical and mental health.	*I was begging them, I was like, can you please … and they refused*
Easier said than done Most women inexperienced in self-advocating and doing so when acutely unwell and vulnerable was especially difficult. It usually took enhanced distress to provoke their assertiveness. Women identified with being "a good patient". There was a lack of awareness of patient rights.	*I wouldn't have been so rude & such a strong advocate for myself, but I was scared…they weren't paying attention… I thought – I'm not dying for anybody.*
Crazymaking When women had their concerns dismissed or invalidated by HCPs they were fearful of possible cardiac outcomes but also started to doubt themselves. Having their lived experiences denied was distressing and undermining. This loss of voice and autonomy increased their vulnerability, sense of impotence and eroded trust in the HCPs.	*Oh, it was terrible. I think it was worse than everything put together. I felt like they were telling me that I was going crazy. I was so lucid.*
Concentric circles of advocacy In time, women found their voice, sought second opinions, increased their knowledge, and defined their expectations. They advocated for themselves, their children, and as they recovered, some advocated for peers and the broader community.	*Yes, it was pretty traumatising but it just made me more determined in my work, to not allow that for anyone else.*



Barriers to self-advocacy

lack of knowledge
- of CDPP by HCPs and women
- of patient rights

lack of support
- little or no peer connection
- within health system generally
- no referral to mental health, counselling

health system
- under-resourced & time-poor HCPs
- fragmented, lack of dedicated services
- HCP individual style

self
- being a "good patient"
- inexperience self-advocating
- hard to advocate in acute situations
- previous negative experiences self-advocating

gender

known issues in
- cardiac disease
- reproductive health
- pain management
- uncommon conditions
- trust in patient story

Conclusion

Self-advocacy is not universally accessible or achievable for all patients, and it may even be unsafe for patients. Transitioning from older care models of medical dominance, paternalistic communication and patient silence is profoundly complex. Transitioning requires patients, health professionals, health systems and broader society to be working towards the same goal, and it is unfair and unreasonable to expect patients to carry the burden of this shift in practice. The experience of having CDPP can be distressing, disorienting and isolating. Regardless of women's individual attributes, knowledge and experience, self-advocating for their health is complex and difficult. The women reported that the inability to have their voices heard had negative cardiac and psychological outcomes. Person-centred care requires patients to be able to advocate and this includes providing professional interactions and an environment to facilitate advocacy .

This is a summary of the article *Is self-advocacy universally accessible, achievable or safe for patients? The experiences of women with cardiac disease in pregnancy and postpartum* (draft)
by J Hutchens, J Frawley and E Sullivan funded by NSW Heart Foundation.

Appendix 10: Heart Foundation report – Mental health of women with cardiac disease in pregnancy and postpartum

mother + heart

MENTAL HEALTH OF WOMEN WITH CARDIAC DISEASE IN PREGNANCY & THE FIRST YEAR POSTPARTUM

Background

Women with cardiac disease in pregnancy and the first year postpartum (CDPP) often face uncertainty about their condition and the trajectory of their recovery. CDPP encompasses a range of congenital, genetic and acquired conditions, including; cardiomyopathies, rhythm disorders, coronary artery dissection and myocardial infarction, structural anomalies and valvular conditions. Cardiac disease is a leading cause of serious maternal morbidity and mortality, and the prevalence is increasing. Affected women are at risk of worsening cardiac disease, chronic illness, mental illness and trauma. This compounded risk may lead to significant and long-term negative outcomes.

There is a lack of information and research on the short- and long-term mental health of women with CDPP.

Methods and data sources

Data were collected from 1) an anonymous online survey, and 2) in-depth qualitative interviews.

The survey used the Depression, Anxiety Stress Scales short version (DASS-21) and cardiac disease-specific Cardiac Anxiety Questionnaire (CAQ). The DASS-21 is a general mental health instrument that differentiates between depression, anxiety and stress. The CAQ is specific for cardiac anxiety, which is apprehension and fear related to cardiac-related stimuli and sensations and has subscales of fear, avoidance and heart-focused attention.

The in-depth interviews were semi-structured and encouraged women to describe their experiences in their own words and to focus on topics more important to them. Data were analysed using thematic analysis.

Participants

Online survey
43 women
mean 5 years since CDPP
Aug 2021 - Nov 2021

Interviews
25 women
mean 5.8 years since CDPP
Dec 2018 - Apr 2020

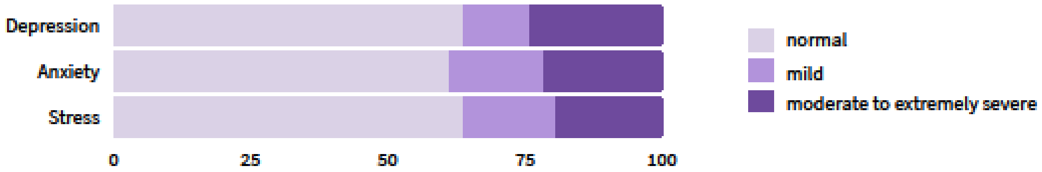
Participants for both studies were recruited using purposive sampling from established Facebook cardiac support groups and cardiac organisations and registries as well as via the study Facebook page.

Inclusion criteria were: Australian residents/citizens at time of CDPP, gave birth to one or babies beyond 20 weeks gestation of at least 400gm birthweight, 18 years or older, and sufficient English language to participate.

Findings

Dass-21

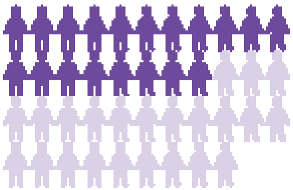
The results from the DASS-21 indicated higher prevalence of depression, anxiety and stress amongst participants compared Australian norms, with mean scores of 4.29 vs 2.57 for depression, 3.41 vs 1.74 for anxiety and 6.27 vs 3.99 for stress and total DASS-21 of 13.98 vs 8.30. Combined scores for moderate, severe or extremely severe rating were 24% for depression, 22% for anxiety and 20% for stress indicating important findings of mental distress.



> *"The first year is really hard ... frightened to death that every night you go to sleep you're going to die.."*

Cardiac Anxiety Questionnaire

There are no validated clinical cut-off scores for the CAQ however a higher scores indicate greater cardiac-related anxiety. The mean total was 1.92 (range 0.83 - 3.06), with subscale means of fear 2.0, avoidance 2.0 and heart-focused attention of 1.7. A score of 1 indicates frequency of cardiac anxiety is rare, a score of 2 indicates frequency is sometimes, 3 is often and 4 is always. Nineteen participants (45.2%) scored at least two, indicating at least moderate cardiac-specific anxiety.



In-depth interviews

Women described complex and distressing experiences that affected their sense of identity and mental health beyond their pregnancy or first year postpartum. In addition, there was a lack of recognition of mental health outcomes and inadequate mental health clinical support.

Regardless of differences in age, cardiac diagnosis and cardiac health status, parity and timing of diagnosis, the stories were consistent across themes of: psychological distress, grief, biographical disruption, loss of self-identity, isolation, a necessitated re-imagining of their lives, and the process of multi-layered healing.

> *"I think it is only years later that the toll has become very evident, for the whole family, in terms of mental health. I think the whole family has struggled with it."*

Conclusion and recommendations

Acknowledging and understanding the breadth, complexity and depth of women's mental health is fundamental to improving outcomes. Findings of these studies provide unique insights and are strongly suggestive of a marked negative mental health impact of CDPP on women. Most women in the interviews reported repeated and ongoing traumas and triggers that extended beyond the first year postpartum.

The disease-specific CAQ identified a greater degree of anxiety than the general DASS-21 inferring a focused rather than generalised anxiety and suggesting a role for information, skills for self-management and counselling support. It also highlights the value of disease-specific instruments. Participants had anxiety, fear, depression and stress specifically regarding their ability to mother with a heart condition, their children developing a heart condition and the risk of foreshortened lives and being unable to raise their children. The development of quality of life and mental health survey tools that are disease- and mother-specific is essential to adequately assess the mental health and support needs of women with CDPP.

It is recommended that mental health screening incorporates maternal, acute and chronic illness factors, and that screening timeframes extend beyond 6 weeks postpartum. Further research is required to understand long-term outcomes and to refine the findings for specific disease cohorts to be able to provide services and support that meet the needs and values of women with CDPP.

This is a summary of two articles: *Cardiac disease in pregnancy and the first year postpartum: a story of mental health, identity and connection* (accepted for publication) , and *Quality of life and mental health of women who had cardiac disease in pregnancy and postpartum (draft)* by J Hutchens, J Frawley and E Sullivan funded by NSW Heart Foundation

Appendix 11: Heart Foundation report – Quality of life of women with cardiac disease in pregnancy and postpartum

mother + heart

QUALITY OF LIFE OF WOMEN WITH CARDIAC DISEASE IN PREGNANCY AND THE FIRST YEAR POSTPARTUM

Background

Cardiac disease in pregnancy and postpartum (CDPP) is under-researched nationally and internationally despite an estimated prevalence of 1-4% (approx. 3 - 12,000 women in Australia annually) and being a leading cause of perinatal morbidity and mortality. CDPP encompasses a range of congenital, genetic and acquired conditions, including; cardiomyopathies, rhythm disorders, coronary artery dissection and myocardial infarction, structural anomalies and valvular conditions. Women with CDPP are at the intersection of the known impacts of cardiac disease and lower quality of life, cardiac disease and poorer mental health, pregnancy and postpartum mental health conditions, specific challenges for younger people and cardiac disease, and mothering with chronic illness.

Studies using patient reported outcome measures are essential in understanding and improving clinical and broader quality of life (QoL) outcomes and are integral to person-centred care and shared decision-making. Patient-reported health status is an independent predictor of subsequent mortality, cardiovascular events, hospitalisation, and costs of care. This has potential implications for risk adjustment and targeting of healthcare resources.

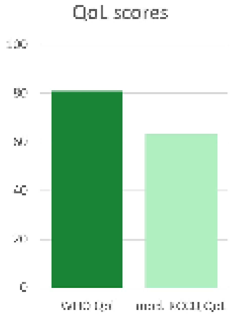
The outcomes of CDPP are not limited to the acute cardiac event or pregnancy, but persist throughout the woman's and her family's lives. There is currently limited tailored clinical, psychosocial or educative support for survivors of CDPP or related resources for the health care professionals caring for them. This exploratory study sought to describe the quality of life of women who had CDPP in Australia.

Data sources and process

Data were collected from an online survey. Overall QoL was assessed using the Australian WHOQoL-Bref questionnaire, which has 2 global questions (overall QoL and health satisfaction) and four domains of physical health, psychological health, social relationships environment. Health-related QoL (HRQoL) was assessed using the Kansas City Cardiomyopathy Questionnaire (KCCQ), modified to apply across cardiac diseases, plus newly developed questions. Participants were 43 women with acquired (n = 25), congenital (n = 11) and genetic heart disease (n = 7). Median age of participants was 31 years (range: 19-39) and mean time since first CDPP was 5 years.

Findings

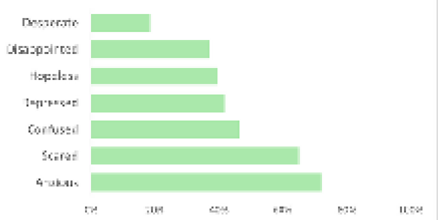
WHOQoL-Bref score QoL as a single question and the KCCQ QoL is a composite score of 3 questions; both are scored out of 100. The mean WHOQoL score for overall QoL was 80.8, compared to the HRQoL from the modified KCCQ mean of 63.1, demonstrating a significant difference when a disease-specific measure is used, and a markedly lower perception of HRQoL.



WHOQolBref

Compared to Australian WHOQoL-Bref norms health satisfaction (51.7 vs 72), physical health (55.2 vs 80.0), psychological health (64.9 vs 72.6) and social relationships (63.0 vs 72.2) were all marked lower in women with CDPP; environment was comparable (72.2 vs 74.8). In the WHOQoL-Bref QoL did not necessarily improve over time: QoL was scored as Poor/Neither good or poor for zero participants whose CDPP was less than 18 months ago, compared to 6 (19.8%) for those whose CDPP was 18 or more months ago. Health satisfaction was scored as Very dissatisfied/Dissatisfied for 4 (40%) for participants whose CDPP was less than 18 months ago, compared to 11 (34.4%) for those whose CDPP was 18 or more months ago.

How women felt when told of their cardiac diagnosis



Did they feel adequate counselling was provided about their diagnosis?

yes 7% | no 93%

KCCQ & additional questions

The modified KCCQ identified important issues relating to information, communication, support, self-management, outlook, mental health, employment and financial concerns. Key findings are:

- Inadequate information given about diagnosis - 37.2%
- Information and advice was unclear - 31.7%
- Received no information or advice re diagnosis - 18.6%
- Ever missed appointments due to difficulty arranging childcare - 40.5%
- Ever missed appointments due to cost (if not free) - 25%
- Stopped or reduced employment due to CDPP - 60%

Family & relationships

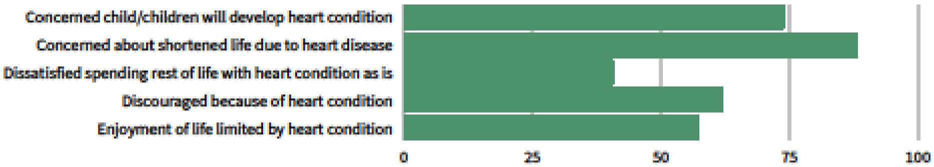
The majority of women were advised to avoid future pregnancies and received no support about this, despite it being very important and distressing, perhaps more so as most were first-time mothers. Most (88.9%) scored receiving this advice as "upsetting" through to "devastating". A further 11.1% said the advice was hard to receive and that they are still upset by it.

Nearly one-third (30.8%) of sexually active women were concerned that having sex would harm or be unsafe for their heart.

first-time mothers	69.8%
advised to avoid future pregnancies	83.7%
said this advice was "Devastating"	44.4%
offered counselling about not being able to have more children	10%

Outlook

Questions relating to overall outlook, concerns and the impact of living with a heart condition were mixed. Women scored high for concern about their longevity and about the children, and were discouraged about their condition. Despite this, they were accepting of spending the rest of their lives with the heart condition as it was at time of the survey and the majority were able to enjoy life despite their condition.



Conclusion and recommendations

These results demonstrate a significant negative impact on the QoL and HRQoL on women with CDPP. Participants had CDPP on average 5 years ago inferring a persistent negative outcome. Responses to diagnosis, advice to avoid future pregnancies, concerns about their longevity and their children's health suggest a role for increased and improved counselling, communication and information, clinical and qualitative research to inform these. Access to healthcare is compromised by a lack of access to childcare and cost. This in turn reflects increased cardiac risk due to the inverse relationship of lower QoL, mental health and reduced access to care and cardiac injury or deterioration. There were inconsistent patterns between categories of disease and small numbers preclude generalising these results. It is recommended that further research be conducted that a) includes a larger cohort, b) refine disease- and lifestage-specific HRQoL instruments, c) is inclusive of diversity of age, location, gender identity, ethnicity and health service usage, and d) is a longitudinal approach. An additional option would be a parallel study on infant outcomes.

This is a summary of the article: *Quality of life and mental health of women who had cardiac disease in pregnancy and postpartum* (draft) by J Hutchens, J Frawley and E Sullivan funded by NSW Heart Foundation

Appendix 12: Heart Foundation report - The ongoing needs of women with cardiac disease in pregnancy and postpartum



mother + heart

THE ONGOING NEEDS OF WOMEN WITH CARDIAC DISEASE IN PREGNANCY AND THE FIRST YEAR POSTPARTUM

Background

Studies on women's health and healthcare experiences are essential to build patient agency, enhance the knowledge of service providers and to inform care provision. Cardiac disease in pregnancy and postpartum (CDPP) is under-researched despite an estimated prevalence of 1-4% (approx. 3 - 12,000 women in Australia annually). CDPP is a leading cause of perinatal morbidity and mortality however the effects are long term as the women have ongoing cardiac disease and the potential for compromised mental health and quality of life outcomes.

We conducted in-depth interviews which identified that women's healthcare needs were not being met. The interviews plus an online survey identified strong themes of isolation, enduring mental health concerns and lack of information to enable self-management and advocacy.

Data sources and process

The interview results informed the development on the online survey, which explored QoL, mental health, mothering and needs. Participants rated the usefulness of 9 listed options for resources and support, and could to provide additional suggestions. Upon completion of the survey participants were invited to contribute to a focus group to explore their needs and suggested resources in greater detail.

in-depth interviews

25 women
identified key gaps & concerns

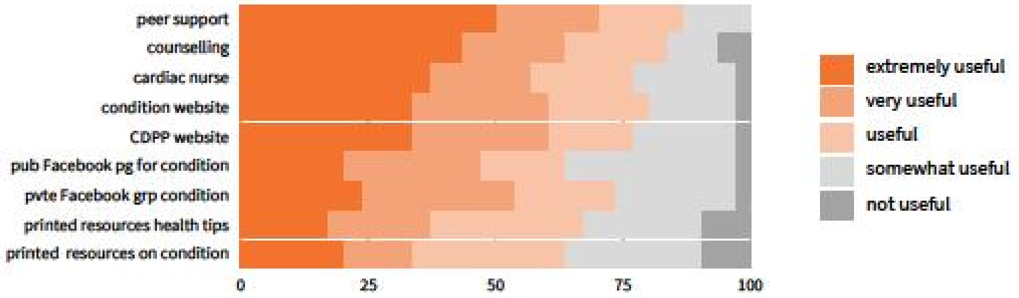
online survey

30 women
completed the needs assessment

focus groups

8 women
explored core resource & support ideas

Survey needs assessment results



Focus group outcomes

PEER SUPPORT

- Peer Support is where people with a shared health condition or situation connect and provide knowledge, experience, and social or practical help to each other.
- Informal peer support occurs through personal contacts, groups moderated by organisations or via social media groups.
- A supported peer support program is facilitated by relevant organisations that provide training and support for peers, and who maintain a database of trained peers. Peer contact can be in person, online or on the phone.

COUNSELLING

- Mental health needs are ongoing; support is needed at onset and at key trigger times in subsequent years (e.g. cardiac events). Key topics included anxiety, depression and PTSD, a sense of health vulnerability, and financial, professional, relationship and mothering stressors due to CDPP.
- Services sought include debriefing and support to reduce the severity and duration of mental distress and trauma, as well as skill development to enhance problem-solving, advocating, stress and anxiety management.

CARDIAC LINK NURSE

- Specialist cardiac nurse available remotely to provide further support and information, eg. information about diagnosis, referral options, specialist services, access to travel rebates. This role would augment existing care, increasing women's ability to manage their health.
- An accessible qualified health professional to provide guidance and support, primarily for women with CDPP but could also be used by health professionals.

The other resources such as a website were considered useful but were considered to be more readily established and would required less planning, development, funding and stakeholder participant than these top 3 items.

Conclusion and recommendations

- There was support for all options discussed with *very strong* responses desiring peer support, counselling and a cardiac link nurse. These options directly address the key findings of isolation, poor mental health and knowledge gaps.
- Peer support: the supported peer support program was perceived to be the most valuable. Peer support reduces the significant isolation, increases support, enables knowledge-sharing, helps define new self-identity and it provides re-assurance to connect with survivors and mothers with heart disease. Moderators of Facebook groups require training and support to fulfil this role.
- Counselling: First contact should occur as soon as possible and be integrated as part of routine care that does not require a woman to initiate. Initial support for support of acute issues and referral for on-going care as required.
- Cardiac link nurse: some participants had experience with a cardiac nurse follow-up (e.g. heart failure clinic nurse) and equitable access to a service specific to women with CDPP was highly valuable.
- At present there is no CDPP prevalence data in Australia; this is essential to quantify the need and plan services, therefore it is recommended that this research is undertaken as a priority. In addition, research is needed to examine the experiences and needs of diverse groups addressing social and environmental determinants of health.
- Women with CDPP have chronic physical illness and addressing the needs identified here will help them manage their health, and reduce the negative mental health impacts of CDPP.

This is a summary of the article *The ongoing needs of women with cardiac disease in pregnancy and the first year postpartum* (draft) by J Hutchens, J Frawley and E Sullivan, funded by NSW Heart Foundation.

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