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Experiences of women with cardiac disease in pregnancy: A systematic review and meta-synthesis

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-022755
Article Type:	Research
Date Submitted by the Author:	08-Mar-2018
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Keywords:	Pregnancy, cardiac disease, women centered care, shared decision-making, qualitative meta-synthesis

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Manuscripts

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3 **Experiences of women with cardiac disease in pregnancy: A systematic review and meta-**
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5 **synthesis**
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28 Word count: 4,591
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ABSTRACT

Objective

Cardiac disease in pregnancy is a leading cause of maternal death in high income countries world-wide. There is a lack of evidence-based guidelines to assist in planning and managing the healthcare of affected women. We conducted a qualitative meta-synthesis to explore the decision-making processes, supportive strategies and health care experiences of pregnant women with existing or acquired cardiac disease, or of affected women contemplating pregnancy.

Method

We analysed qualitative peer-reviewed data to extract the experiences of women in the literature by a systematic search of five bibliographic databases using appropriate keywords. Identified publications were screened for duplication and eligibility against selection criteria, following the PRISMA guidelines. We then undertook a thematic analysis of the data relating to women's experiences extracted from each included publication.

Results

Eleven studies from six countries were included in our meta-synthesis. Four emergent themes were revealed. Women with congenital and acquired heart disease identified situations where they had either taken charge of decision-making or lacked control, or experienced emotional uncertainty when making decisions. Some women were risk aware and determined to take care of themselves in pregnancy while others downplayed the risks. Women with heart disease acknowledged the importance of specific social support measures during pregnancy and after child birth and reported a spectrum of health care experiences.

Conclusions

1
2
3 There is a lack of integrated and tailored healthcare services and information for women
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5 with cardiac disease in pregnancy. The voice and experiences of women should inform new
6
7 evidence-based guidelines to support their decision-making needs. Shared decision-making
8
9 must consider communication across the clinical team. However, coordinated care can be
10
11 challenging due to the different specialists involved and the limited clinical evidence
12
13 concerning effective approaches to managing such complex care. Research is needed to
14
15 provide evidence for gendered approaches to shared decision-making in cardiac care.
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21 **Keywords:** Pregnancy, cardiac disease, women centered care, shared decision-making,
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23 qualitative meta-synthesis.
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28 **Article Summary**

29 **Strengths and limitations of this study**

- 30
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- 33 • This is the first meta-synthesis of qualitative research to investigate the experiences
34 of pregnant women with a spectrum of cardiac disease.
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 - 37 • The small number of studies in this synthesis demonstrates the paucity of qualitative
38 research in this area, particularly the voices of pregnant women with genetic
39 conditions.
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 - 43 • The thematic analysis enabled patterns to be discerned that may be translated to
44 cardiac disease in pregnancy and potentially other rare and chronic diseases in
45 pregnancy.
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 - 49 • Our multi-disciplinary research team enabled a rich and detailed yet complex
50 account of the extracted data.
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INTRODUCTION

Cardiac disease in pregnancy is a leading cause of maternal death in the developed world. In the United States, pregnancy related deaths due to cardiovascular disease were ranked as the leading category of death for 2011 to 2013 at 15.5% [1]. In the United Kingdom the rate of maternal deaths associated with cardiac disease has more than doubled from 1.0 in 1985 to 2.3 per 100,000 maternities in 2008 [2]. In Australia, cardiac disease in pregnancy has been the leading cause of indirect maternal deaths for almost 50 years [3 4], and a common cause of late maternal death [4 5].

Cardiac disease in pregnancy constitutes a broad spectrum of conditions, including: congenital (e.g. ventricular septal defect, transposition of the great vessels); genetic heart diseases (e.g. hypertrophic cardiomyopathy, long QT syndrome, Brugada syndrome); chronic arrhythmia conditions (e.g. Wolff Parkinson White syndrome); as well as heart diseases acquired before or during pregnancy (e.g. rheumatic heart disease, ischemic heart disease, peripartum cardiomyopathy). Heart transplants can also affect pregnancy outcomes.

Cardiac disease in pregnancy is associated with high rates of morbidity and hospitalization: 15% of women in Europe have been admitted for cardiac indications during pregnancy [6]. Approximately one in four women with cardiac disease in pregnancy are hospitalized during pregnancy, and overall cardiac disease in pregnancy is associated with increased likelihood of eclampsia, caesarean birth and postpartum hemorrhage [6]. For the baby there is an increased likelihood of stillbirth, preterm birth and acquired congenital disease [6]. The European Registry of Pregnancy and Cardiac Disease has reported significant

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3 adverse perinatal outcomes for both mother and baby, most notably a maternal mortality
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5 rate of one percent, which is more than 100 times the rate for women without cardiac
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7 disease.
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12 Confidential death enquiry data from the UK suggest there are an increasing number of
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14 women who die from the combination of pregnancy and cardiac disease [2]. There are
15
16 several possible explanations for this observation including: the improved survival (~90%) of
17
18 children with congenital heart disease to adulthood; increased awareness and diagnosis of
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20 genetic conditions; lifestyle factors (e.g. obesity) and older maternal age associated with
21
22 ischemic heart disease [7-9].
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28 Pre-conception counseling for women with chronic health issues is essential however, many
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30 women with cardiac disease have been found to have high rates of unintended
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32 pregnancies[10 11] that may indicate issues concerning health professional attitudes
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34 towards providing such counseling and gaps in women's contraceptive knowledge and
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36 available decision support.
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42 Despite clinical available guidelines [12-14] limited knowledge exists regarding the health
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44 care, support and decision-making experiences of women with cardiac disease who are
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46 pregnant, or contemplating pregnancy. Insights into women's experiences of planning and
47
48 undergoing pregnancy including their perceptions and satisfaction are critical to the
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50 provision of health services, care and information.
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3 This paper aims to synthesize the qualitative evidence and deliver insights on how to best
4 support the decision-making of women with cardiac disease and the unique opportunity for
5 health professionals to strengthen quality of cardiac care from pre-conception planning to
6 the postnatal period.
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11 12 13 14 **Methods**

15 16 *Data sources and search strategy*

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18 We undertook a qualitative systematic review of the literature and conducted a meta-
19 analysis, following methods outlined by Thomas and Harden[15] to address the question:
20
21 What are the experiences of women with existing or acquired cardiac disease who are
22 pregnant, or contemplating pregnancy? Our goal was to identify the decision-making
23 processes and interactions with health professionals that women with cardiac disease in
24 pregnancy experienced to gain insights into their resilience including coping strategies.
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34 We used the PRISMA statement (Figure 1) with a cut-off date of 2016. We searched the
35 literature available in five, on-line, bibliographic databases: CINAHL Plus (1995–October
36 2016); Embase (1996–October 2016); Ovid MEDLINE (1996–October 2016); PsycINFO (1984–
37 October 2016) and the Joanna Briggs Institute Evidence Based Practice Database
38 (1996–October 2016). Boolean operators (and, or, not) were used to refine our search with
39 the following keywords: cardiac disease; pregnancy, pregnant women, decision-making and
40 shared decision-making. Publications that met our selection criteria (Table 1) were further
41 analyzed. We also searched for publications in Google Scholar and manually from the
42 reference lists of key papers that identified an additional 19 relevant publications. See
43 Appendix 1 for details of the bibliographic search strategy.
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Figure1. PRISMA Flowchart of Cardiac Disease in Pregnancy

Table 1. Inclusion and exclusion criteria used to identify publications that involved women with cardiac disease in pregnancy

Inclusion criteria	Exclusion Criteria
The experiences of women of reproductive age with existing or acquired cardiac disease in pregnancy who are, or have been pregnant or contemplating pregnancy. This included preconception, prenatal, intrapartum, perinatal and postnatal periods.	Women with cardiac disease who were not of reproductive age or who have not been or contemplated pregnancy
Qualitative studies	Quantitative studies
Mixed methods design with a qualitative component	Clinical studies of cardiac disease in pregnancy
Published in the English language	Non-English articles

Quality assessment and data extraction

Nineteen potentially relevant publications were identified. Of these, eight were excluded because they were either not pertinent to our review or not peer-reviewed (e.g. PhD thesis).

The six qualitative publications and the qualitative components of the five mixed methods publications were appraised using the Critical Appraisal Skills Program (CASP) qualitative checklist [16] by two authors (AD and YK). Each paper was independently assessed using a table with the ten CASP questions to comment on the available detail on the data sampling,

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3 collection and analysis processes and the coherence of the paradigm underpinning the study
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5 involving the fit between data gathered and the conceptual work of analysis and
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7 interpretation. Despite the methodological limitations of some papers including gaps in the
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9 discussion of reflexivity and credibility all 11 papers were included in the meta-synthesis as
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11 it was deemed that their strengths outweighed these issues. Data from the findings sections
12
13 of the publications that specifically concerned the preconception planning and pregnancy
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15 experiences of women with cardiac disease, were extracted for further analysis. This
16
17 included direct quotes and text describing related findings.
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21 *Data analysis*

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23 The extracted text was coded 'line-by-line' by two authors (AD and YK) and then descriptive
24
25 categories developed that aligned with the original studies. The concepts from the
26
27 descriptive categories were grouped into themes and sub themes, and conceptual links
28
29 among themes were identified. Tables were used for this process. First text was marked
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31 using color highlighting from each study and descriptors used to categories emergent
32
33 concepts within each paper. These descriptors were then compared across papers and
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35 synthesized into one table. This led to the conflation of descriptive themes and the
36
37 development of emergent categories whose meaning was refined in order to answer the
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39 review questions and address the aim of the study [17].
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44 *Patient and Public Involvement*

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46 Qualitative patient data is the focus of this synthesis however, patients and the public were
47
48 not involved in the design of the study or analysis of the data. The results of this study will
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50 inform the design of a research project that will involve the co-production of tools and
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52 educational materials for women with cardiac disease in pregnancy.
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RESULTS

A summary of the methodology and findings of the 11 studies used in this review is given in Table 2. The studies were conducted across six countries: The United States of America (n=5), Australia (n=2), Sweden, (n=2), Canada (n=1), Norway (n=1) and Belgium (n=1). Six studies comprised qualitative designs [18-23] while five used mixed methods [24-28] (See Table 3).

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Table 2. Summary of the methodology and data of the 11 publications used in this review

Publication	Methods	Aim	Findings
Andersen et al. [18]	Qualitative: in-depth face to face interviews	To investigate psychosocial aspects of living with Long QT Syndrome(LQTS); to identify LQTS patients’ daily challenges and coping strategies; and to describe LQTS patients’ experience with healthcare services.	The main concern of the patients with LQTS was that something might happen to their children and grandchildren. Participants favored early genetic testing, and the provision of early and gradually presented information about LQTS for children.
Claessens et al. [19]	Qualitative: unstructured, in-depth interviews	To explore the lived experiences of adult congenital heart disease patients.	The central theme of the patients’ lived experiences was “feeling different”. Patients struggled constantly with themselves and with their environment to be accepted as normal.
Dekker et al. [22]	Publicly available narratives in 3 online support groups.	To describe the experience of women diagnosed with Peripartum Cardiomyopathy (PPCM).	Nearly 40% of women felt that they were dismissed by health-care providers. Women had difficulty caring for their newborns during the postnatal period, and they struggled with the medical advice they received to not conceive again.

Publication	Methods	Aim	Findings
Gantt 1992 [21]	Qualitative: unstructured face to face interviews; Grounded-Theory	To generate an understanding of, and theories about, the lives of women with congenital heart disease.	Lack of information related to women's bodies and reproductive issues ("growing up female"). Over involvement of mothers and health care professionals in the affairs of the child's and woman's body, resulting in decreased ownership of the body by the woman ("living against the body"). Poor self-esteem, self-concept, and body image ("growing up heartsick"). A need for various types of counselling for women with congenital heart disease was identified.
Gantt [20]	Qualitative descriptive design with unstructured interviews.	To study the effect of congenital heart diseases on the mother–daughter relationship.	Overriding theme of the study was normalizing in the face of chronic illness, with a tendency by the mothers and daughters to focus on their lives instead of their relationship with one another.
Hess et al. 2010 [26]	Descriptive study: a survey of open-ended and Likert-type questions.	To determine the benefits of participation in the online support group for peripartum cardiomyopathy based on a survey of active members of the group.	One of the most important issues facing women with peripartum cardiomyopathy is future childbearing. The benefits of participation in the online support group included getting and sharing information, exchanging stories, being understood by other women and gaining hope.
Hess et al. 2012 [27]	A mixed method design. Analysis of social media postings made by 156 people.	To describe the contents of postings made on the My Space® peripartum cardiomyopathy support group Website by women with peripartum cardiomyopathy.	The subject of pregnancy subsequent to the diagnosis of peripartum cardiomyopathy was mentioned 102 times (amongst 247 posts), making it an issue that was foremost in the minds of many women.

Publication	Methods	Aim	Findings
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Publication	Methods	Aim	Findings
Ngu et al. [25]	A retrospective descriptive study. Mixed method study	To assess the perceptions of women with congenital heart disease regarding the severity of their cardiac abnormality and its implications in pregnancy, and whether their motivations to conceive were like those of women without congenital heart disease.	The women’s personal experience of successfully living with their heart condition influenced their perception of the pregnancy risks. Women with congenital heart disease were concerned about the health risks associated with their congenital heart disease and that of their child.
Ngu et al. [24]	Case Studies Mixed method study.	To understand the motivations of women with congenital heart disease to bear children, and to assess if there are any differences between the cohort with low risk and those with high risk heart disease.	Women with high risk (moderate to severe) congenital heart disease appeared to have similar motivations for conceiving as women with low-risk (mild) congenital heart disease Their drive for motherhood appeared to be stronger than the drive for self-care.
Patel, Berg et al [28]	Mixed method study: qualitative face to face and telephone interviews and review of medical records.	To explore and describe women’s experiences of symptoms in peripartum cardiomyopathy.	Being caught in a spider web comprising the invasion of the body by experienced symptoms and feeling of helplessness.
Patel, Schaufelberge et al. [23]	Unstructured qualitative interviews	To explore women's experiences of health care while being diagnosed with peripartum cardiomyopathy.	The main theme was, 'Exacerbated Suffering', expressed in three subthemes; 'not being cared about', 'not being cared for' and 'not feeling secure'.

Table 3. Summary of the conditions, participants, study locations and year of publication of the 11 publications used in this review

Publication	Condition		Country & Year	Number of participants	Age range (years)
	Congenital heart disease	Other acquired heart disease			
Andersen et al. [18]	Long QT Syndrome		Norway, 2008	Adults (n=7): 4 women; 3 men	23-76 years
Claessens et al. [19]	Moderate or severe heart defects: such as Tetralogy of Fallot; univentricular heart; VSD and aortic valve stenosis; transposition of the great arteries.		Belgium, 2005	Adult patients (n=12): 6 women; 6 men	25-40 years
Dekker et al. [22]		Peripartum Cardiomyopathy	USA, 2016	Adult women (n=92): 1 st pregnancy (n=49), 2 nd pregnancy (n=24), 3 rd pregnancy (n=10), >4 th higher pregnancy (n=8), and unreported (n=1).	17-41 years
Gantt 1992 [21]	Transposition of the great vessels (TOGV), pulmonary atresia, atrial septal defect (ASD), double outlet right ventricle, pulmonary stenosis, truncus arteriosus, and coarctation of the aorta.		USA, 1992	Adolescent, young adults (n=13).	13-15 years old (n=3), 16-18 years old (n=4), 19-21 years old (n=3), 22-28 years old (n=3).
Gantt 2002 [20]	One woman with childhood rheumatic fever, one adolescent woman had a heart murmur only. All others had congenital heart diseases of varying types and severity that had been surgically repaired or palliated.		USA, 2002	Adults and children (n=22): 11 mothers and 11 daughters.	Daughter's school-age, the youngest was 9 years. Mothers' age range from 30-60 years.

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Publication	Condition		Country & Year	Number of participants	Age range (years)
	Congenital heart disease	Other acquired heart disease			
Hess et al. 2010 [26]		Peripartum Cardiomyopathy	USA, 2010	Adult women (n=12). 7 women didn't have other children prior to the diagnosis.	19 to 34 years
Hess et al. 2012 [27]		Peripartum Cardiomyopathy	USA, 2012	Adults (n=156). 148 (95%) women with PPCM; 8 (5%) husbands, mothers, sisters and grandmothers.	Mean age 27 years.
Ngu et al. [25]	Mild: pulmonary atresia; moderately large VSD; transposition of the great vessels; coarctation of aorta; bicuspid aortic valve; Ebstein's anomaly of tricuspid valve. Moderate: Tetralogy of Fallot; mitral valve dysplasia, sub aortic stenosis. Severe: VSD; aortic valve stenosis; double outlet right ventricle.		Australia, 2014	Women with (n = 20) or without (n = 20) CHD aged >18 years, who had ≥1 successful pregnancy.	Women with congenital heart disease- mean age 32.6 ± 5.3 years; Women without congenital heart disease- mean age 33.9 ± 5.2 years.

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Publication	Condition		Country & year	Number of participants	Age range (years)
	Congenital heart disease	Other acquired heart disease			
Ngu et al. [24]	Mild: pulmonary atresia; moderately large VSD; transposition of the great vessels; coarctation of aorta; bicuspid aortic valve; Ebstein's anomaly of tricuspid valve. Moderate: Tetralogy of Fallot; mitral valve dysplasia; sub aortic stenosis. Severe: VSD; aortic valve stenosis; double outlet right ventricle		Australia, 2014	Women with mild CHD (n = 10) with: 1 child (n = 4) 2 children (n = 4) 3 children (n = 2). Women with moderate to severe CHD (n = 10) with: 1 child (n = 5); 2 children (n = 3); 3 children (n = 2).	Women with mild –CHD-mean age 35.8 ± 5.9 years, Women with moderate to severe CHD - mean age 28.9 ± 3.5 years.
Patel, Berg et al. [28]		Peripartum Cardiomyopathy	Sweden, 2016	19 women	28–46 years*
Patel, Schaufelberge et al. [23]		Peripartum Cardiomyopathy	Sweden, 2016	19 women	28–46 years*

*Separate studies drawing upon data from the same cohort of women

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Four themes and seven sub-themes emerged from our meta-analysis, which are summarized in Table 4 and described in more detail below.

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Table 4. Frequency of themes in women with cardiac disease in pregnancy identified in the literature

Reference	Themes:	Women's autonomy and control				Self-care and risk awareness in pregnancy	Social support for decision-making	Health care experiences		
		Sub-themes:	Taking charge of decision-making	Lack of control	Emotional uncertainty of decision-making			Helplessness, fear and vulnerability	Health information needs	Responsive care
Congenital heart disease										
Andersen et al [18]	✓	✓	✓	✓	✓	✓	✓			
Claessens et al. [19]	✓		✓	✓						
Gantt 2002 [20]	✓				✓					
Gantt 1992 [21]	✓		✓		✓			✓		✓
Ngu et al. [24]					✓	✓			✓	
Ngu et al. [25]	✓				✓	✓				
Other acquired heart disease										
Dekker et al. [22]			✓	✓	✓			✓	✓	✓
Hess et al. 2010 [26]	✓					✓	✓	✓		✓
Hess et al. 2012 [27]	✓						✓			✓
Patel, Berg et al. [28]				✓	✓					
Patel, Schaufelberge et al. [23]					✓				✓	✓

Women's autonomy and control

Taking charge of decision-making

Some women expressed their determination to take control and make their own decisions regarding their pregnancies. One woman was resolute to try to fall pregnant and if unsuccessful wanted to consider other options: "I want to give birth to at least one child. I want to have the opportunity to do that, then later I can adopt ..." [18]. Another woman became pregnant two months after her diagnosis of heart disease and described being "told to terminate her pregnancy" but she "refused" [27]. Another woman felt she "had lived a good life" and her disease "could not be considered a reason for terminating a pregnancy" [18]. The positive thinking that "life isn't over just because you have peripartum cardiomyopathy" and the possibility of having more children was a key factor driving the decision of women who went through another pregnancy and "received a beautiful little girl in exchange" [26].

Women's trust in their clinicians and their experiences of successfully adapting to their congenital cardiac disease by developing coping mechanisms, played a role in their desire to make their own decisions and proceed with their pregnancies [25]. Some women felt that they had to take responsibility not only for their own health, but also for that of future generations. These women undertook genetic testing as early as possible [18] to prevent giving birth to a child with congenital heart disease [21].

Women desired to take control and live a "normal life" [20 24], participate in social activities and "fit in" [21]. This often stemmed from childhood experiences of being excluded and "feeling different" [21]. For some women, this motivated them to make their own decisions

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3 and to take on new and different activities as a means of coping “ I do these things just to
4
5 challenge those boundaries, limitations” [19].
6
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8 9 *A lack of control*

10
11 In contrast, a lack of autonomy and control was noted by women in relation to pregnancy
12
13 decision-making. Some women believed that someone else would decide whether they
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15 should become pregnant in response to being “told right from the beginning not to have any
16
17 more children” [22]. Another woman felt that she had no choice and could not take the risk
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19 and have her family shoulder the burden of another episode of heart failure [21]. Others
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21 described feeling how social pressure and the judgment of others interfered with their
22
23 decision to have more children: "you're not supposed to get pregnant when you have
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25 congenital heart disease” [21]. Another woman, who already had a child diagnosed with
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27 heart condition, feared being perceived as “selfish” [18].
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35 For some of the women, their heart disease defined and dominated their decision-making
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37 [18]. One woman talked of how everything in her life "came down to the heart" [21]. While
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39 another described the tension between the control their disease had over them, and their
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41 own autonomy to make decisions, including those about pregnancy “I do make plans and
42
43 that sort of thing, but I don't dare to carry them out. Now I understand that ...I must start
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45 something independently ...but I'm scared” [19]. A lack of autonomy and control was
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47 discussed by women in relation to financial hardship. Some women said that they had
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49 registered for disability payments after their diagnosis and were concerned that they would
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51 not be able to work after giving birth and contribute to the household income due to impact
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3 the pregnancy would have on their physical and mental health. As a result, these women
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5 felt they would be financially dependent upon others [22].
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9 10 *The emotional uncertainty of decision-making*

11
12 In three studies, women described the emotional uncertainty of their pre-conception
13
14 decision-making in highly emotional terms, where they were at a loss regarding what to do
15
16 [18 19] with one women asked 'Is it worth it having a baby?' [28]. Women expressed
17
18 feelings of being depressed, devastated, experiencing "emotional torture ",feeling
19
20 "hysterical" when they were diagnosed with cardiac disease and advised by their doctors
21
22 against future pregnancies [22]. These circumstances required them to re-think their
23
24 situation [22]. Several women described the decisions regarding pregnancy and childbirth as
25
26 extremely difficult for them [18] due to uncertainty regarding the progression and prognosis
27
28 of their disease [19].
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32 33 *Helplessness, fear and vulnerability*

34
35 The feeling of helplessness and loss of control in relation to the development of cardiac
36
37 disease symptoms both during pregnancy, birth and postpartum was expressed by one
38
39 woman as like "being caught in a spider web" [28], or being trapped by their condition and
40
41 fearful about future pregnancies [20]. Another woman described being pregnant as a
42
43 "constant struggle between hope and helplessness" [28]. There was a mix of physical and
44
45 emotional symptoms when women described the suffering of their own illness and the
46
47 inability to take care of their newborn baby [22 23].
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52
53 Women feared dying. They were deeply concerned that they would not survive the
54
55 pregnancy and that they would leave their child motherless, [21 24 25] or be left disabled
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3 and unable to care for their newborn [24]. They were worried about passing on heart
4
5 disease to their unborn baby [18 24], giving birth to a baby with a heart abnormality, [21 24]
6
7 and the effect that medications might have on their baby [21]. These fears deeply affected
8
9 women, so much so that some continued to relive the distress brought on by the diagnosis
10
11 of cardiac disease in pregnancy through flashbacks, years after the birth of their child [23].
12
13

14 15 16 17 **Self-care and risk awareness in pregnancy**

18
19 Risk awareness and desire for motherhood were discussed in four of the papers [18 24 25
20
21 27]. In a study by Andersen et al. [18] women with Long QT syndrome reported being
22
23 frustrated not to know how much danger to their health a pregnancy might impose. They
24
25 felt that if they took the risk to become pregnant, the decision was theirs.
26
27

28
29
30 For another group of women with congenital heart disease, the determination to have a
31
32 child was so strong, that it outweighed self-care considerations. Despite being aware of the
33
34 complications during pregnancy, 10 of the 20 women in the study perceived their disease to
35
36 be less severe than that reported by their clinicians. These women therefore down played
37
38 the seriousness of their condition that was found to be related to a reliance on the care of
39
40 their health professionals, and a belief that medical and surgical care would result in a
41
42 successful pregnancy and birth outcome. This distorted view of their condition was also
43
44 linked to their quality of life which they felt was good [24].
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51 **Social support for decision-making**

52
53 A feeling of empowerment and hope provided through social support was clearly
54
55 demonstrated in several publications analyzed in this review. Women using an online
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2
3 support forum felt that “It is beneficial to know that you are not alone” [26]. Women
4
5 identified the benefits of “friendly, open arms” that “gave me hope”, [26] and others
6
7 iterated “there is always hope” [27]. Some women shared the positive feeling of being able
8
9 to talk to someone who could understand them without judgment and to shared
10
11 experiences. Women found peer-education to be an important part of managing their life
12
13 and living with heart failure [26]. Another woman described the distress of having to face
14
15 her pregnancy decision-making alone, as she lacked support from her family, who did not
16
17 want her to take any risks [18].
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23 **Health care experiences**

24 *Health information needs*

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26 Our review revealed gaps in the understanding of women’s health information knowledge
27
28 or needs by clinicians. Several women felt that they had received inadequate information
29
30 from clinicians. Only six of the participants in one study had information about
31
32 contraception as it related to their heart disease [21]. One woman stated that she was
33
34 “shocked” that none of her clinicians had discussed the severity of her condition with her: “I
35
36 thought I was completely fine. I didn’t know I wasn’t supposed to have any more kids” [26].
37
38 The need for appropriate information delivery and counselling was highlighted by one
39
40 women who recounted the time of extreme panic when her doctor delivered her diagnosis:
41
42 “With no family present, he told me that I might need a heart transplant and that I was
43
44 finished being pregnant” [22].
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53 *Responsive care*

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3 Many women felt that they had received supportive care from their healthcare team, were
4 grateful and praised the skills and responsiveness of their clinicians. One woman expressed
5 this by stating that the “*world's elite team was there for me during the labour*” [23]. Another
6 group of 13 women shared how grateful they were to the nurses who brought their
7 newborn babies to the intensive care unit where they were staying, and recognized the
8 separation concerns [22]. Women also reported feeling “secure” when provided with the
9 phone number of a cardiac nurse or cardiologist to call if they were worried or had
10 questions. Women valued check-ups as these gave them “hope” [23]. Women trusted their
11 clinicians and perceived them to be compassionate professionals who would carefully
12 monitor and support them throughout their pregnancy [24].
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28 *Listening to women*

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30 Women commented on situations where clinicians had overly relied on the results of
31 objective tests and careful monitoring throughout their pregnancy to manage their
32 healthcare, rather than listening to them and taking their experiences and feelings into
33 consideration [23]. Some women reported that their voices were dismissed: “they didn’t
34 seem to care.” [22]; “they did not listen to me”; and “did not respect my wish.” [23]. As a
35 result, women felt ignored, or misjudged, which caused sadness, insecurity and
36 disappointment in the service provided by their healthcare professionals. Women expressed
37 feeling rejected by clinicians and felt that they were treated “like a drug addict; “like a pile
38 of garbage” [23]; “like a baby” [21]. One woman suggested that clinicians learn more about
39 the symptoms of their condition and take the complaints of their patients seriously [26].
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55 **DISCUSSION**

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3 This is the first meta-synthesis of qualitative research to investigate the experiences of
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5 pregnant women with a spectrum of cardiac disease. It provided insight into the continuum
6
7 of preconception, pregnancy and parenting decision-making of those women and the
8
9 unique opportunity for health professionals to strengthen quality of cardiac care. It details
10
11 women's struggle to gain autonomy and control over their decision-making and how this
12
13 may present challenges to self-care during pregnancy and impact on activities of daily living.
14
15 The level of autonomy and control was the most prevalent theme across the cardiac
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17 conditions included; reflecting the need for women centred care.
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24 Our findings are consistent with the experiences of women with other non-communicable
25
26 diseases in pregnancy, such as chronic kidney disease and diabetes [29 30] and similar to
27
28 studies of non-pregnant women with cardiac disease, providing further evidence of the
29
30 importance of women-centered care [31 32]. The American Heart Association emphasizes
31
32 the importance of measuring the self-reported health status (i.e. symptom burden,
33
34 functional status, and health-related quality of life) of patients with cardiac disease as it is
35
36 not only a necessary component of clinical risk scoring, but consistent with a holistic view of
37
38 health and the goals of patient centred care [33].
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44 This review identified opportunities to improve shared decision-making; a central
45
46 component of women centred care that requires clinicians to understand the women's
47
48 social context (her family, employment and other responsibilities) and her goals, values, and
49
50 preferences for health. Shared decision-making can facilitate effective communication
51
52 between a woman and her clinician to develop a shared understanding of the problem and
53
54 generate a mutually acceptable evaluation and management plan. In five of the studies in
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3 our meta-synthesis, women identified as barriers to satisfactory care a lack of clinician
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5 understanding of and attention to women's existing knowledge, as well as women's self-
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7 reported health status and health needs [21-23 26 27]. While suggestions have been made
8
9 about how shared decision making can be implemented into cardiovascular care [34 35] and
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11 translated into practice in national programs such as the Million Hearts® initiative [36 37], a
12
13 gendered approach has not been noted, nor examined in the unique context of various
14
15 cardiac conditions in pregnancy.
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21 Clinicians could be better supported to facilitate a woman's active role in decision making at
22
23 the point of care by using tailored tools, particularly where a woman's self-care may be
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25 affected by downplaying their cardiac disease as found in two studies in the meta-synthesis
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27 [24 25]. Other studies have found non-pregnant women to minimize their conditions [31]
28
29 and hence gendered tools that incorporate collaborative deliberation [38] or conversations
30
31 between women and clinicians, maybe useful more broadly in the care of women with
32
33 cardiovascular disease. The Elwyn et al. "Talk model" [39] may provide a useful conceptual
34
35 framework for shared decision-making that enables measurement across four components
36
37 to facilitate effective communication and its on-going evaluation between a woman and her
38
39 clinician. However, women also have a responsibility to contribute to a charting a clear path
40
41 through decision-making by identifying barriers to their implementation and solutions to
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43 these [40]. Even though this framework provides a practical way forward for clinicians and
44
45 women, it does not consider the steps or processes required for implementation including
46
47 buy-in at the individual clinician and practice level, integration into the workflow and
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49 evaluation, [34] particularly in the context of cardiac disease in pregnancy. Consideration
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51 also needs to be given to how shared decision making and relevant tools can be
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3 incorporated into existing guidelines or consensus statements for the management of
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5 women with cardiac disease in pregnancy to guide health professional practice [12].
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10 The evidence shows that such tools can increase patient participation and improve accurate
11
12 risk perceptions when examples of such risk-based situations are included in decision aids
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14 [41 42]. Women should be engaged in the co-design of materials to ensure beneficial effects
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16 on health behaviour and health status [43]. Shared decision-making must however, also
17
18 consider communication across the clinical team that may include cardiologists,
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20 obstetricians, maternal-fetal medicine specialists, obstetric physicians and anaesthetists,
21
22 intensivists, midwives and cardiac nurses. Patel et al reported that women who received
23
24 high-quality care from teams of health professionals noted that effective communication
25
26 had led to responsive and tailored care [23]. However, a coordinated team approach to
27
28 caring for women with cardiac disease in pregnancy can be challenging due to the distinct
29
30 specialist areas involved and the limited clinical evidence concerning effective approaches
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32 to managing such complex care. These challenges may lead to fragmented care and
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34 variation in the quality of care.
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42 The voices of women in the papers revealed high levels of distress and emotional tension
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44 when a diagnosis of a life-threatening condition was received when they were pregnant or
45
46 contemplating pregnancy. Women also expressed fear of death and disability, and they felt
47
48 helpless and dependent upon others. These findings concur with the reflections of nurses
49
50 who cared for women with cardiac disease in pregnancy who also reported that decision-
51
52 making for many women was “emotionally charged”. Nurses stated that women in a US
53
54 study were concerned about securing stable employment, having sufficient financial
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3 resources to investigate international adoption, providing a good home for the baby, being
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5 good parents, and balancing work responsibilities with the care of children [44]. The meta-
6
7 synthesis findings are also in line with the experience of women with other serious diseases
8
9 in pregnancy [29 45] and highlights the need to not only console women and allay their
10
11 fears, but to support them to build confidence and resilience through coping and self-care
12
13 strategies.
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19 Our review provides little insight into pre-conception counselling and the advice clinicians
20
21 provided concerning contraception for women with existing cardiac disease or after a
22
23 pregnancy where cardiac disease was diagnosed. Gaps in women's knowledge have been
24
25 noted in other studies [46 47] with Vigil et al. demonstrating in one study that less than 50%
26
27 of women with cardiac disease had received any counselling [48]. Miner emphasized the
28
29 importance of including contraceptive counselling early in adolescence on an "on-going
30
31 basis"[49]. The American Heart Association and others provide recommendations regarding
32
33 prenatal counselling for women and their families with heart disease, as well counselling in
34
35 relation to the expectant child that takes into consideration feeding and growth issues,
36
37 quality of life and long-term care, family stressors, and fetal cardiac interventions [12 50].
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44 Empathetic health professional counselling is a central component of health care that
45
46 requires professionals to relay clinical risks and realities while also taking the emotional
47
48 vulnerabilities, values and beliefs of women into consideration across the reproductive life
49
50 span [44]. Little is known about how health professionals can support women with cardiac
51
52 disease in pregnancy to build resilience and self-efficacy.
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3 In our review, the timing of a woman's diagnosis of cardiac disease and hence her
4
5 experience was different depending on the type of condition. Most of those with congenital
6
7 heart disease would have been expected to have knowledge of their conditions, and ideally
8
9 would have had pre-conception counselling. However, for those with peripartum
10
11 cardiomyopathy, the diagnosis may have occurred late in pregnancy, meaning that some
12
13 women would have entered pregnancy without cardiac disease and experienced a very
14
15 different pregnancy until diagnosed and hence having different counselling needs. However,
16
17 many women with peripartum cardiomyopathy present post-partum [51] and therefore
18
19 these women's counselling needs would reflect the consideration of subsequent
20
21 pregnancies.
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29 Counselling may be enhanced by positive relationships between women and their health
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31 professionals. In our review women said they trusted their clinicians and noted the caring
32
33 response of nurses and midwives, especially in enabling women to spend time with their
34
35 babies in hospital [22]. Women with serious medical issues in pregnancy have described the
36
37 importance of having a relationship with a known health provider [30 52] who could identify
38
39 their specific needs and positive opportunities for health and well-being rather than "all
40
41 doom and gloom" that were noted to be empowering [30]. Social workers can also play an
42
43 important counselling role in these contexts.
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49 The health benefits of social support for pregnant women from their partner, family, friends
50
51 and those who have experienced similar circumstances are well known [53] and a significant
52
53 predictor of health-related quality of life. Other authors have highlighted the importance of
54
55 peer mentoring for pregnant women with defined health needs to allay fear and anxiety
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2
3 including for women with spinal cord injuries [52 54]. Strong on-line health care social
4
5 networks have also been found to be important in the provision of emotional support for
6
7 patients with cardiovascular disease [55]. Women in two papers in this review [26 27] found
8
9 on-line blogs to be a helpful way to enable contact with those beyond their immediate
10
11 networks. Other studies found on-line forums to be supportive for other pregnant women
12
13 with rare or life-threatening conditions in pregnancy [56].
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18 Our review points to the need for gender specific models in cardiac disease that can inform
19
20 the development of decision-making tools and with the input of women, can better harness
21
22 opportunities to facilitate the development of women's resilience, self-care and social
23
24 support.
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30 Of the 11 studies included in this meta-synthesis (see Table 3) there were a total of 383
31
32 women participants with the following conditions: congenital heart disease (n = 81);
33
34 peripartum cardiomyopathy (PPCM) (n = 298), and Long QT syndrome (n = 4). The voices of
35
36 pregnant women with genetic conditions appeared to be absent from the literature, as well
37
38 as those from other than high-income countries. Thus, there is limited generalizability
39
40 across all cardiac disease in pregnancy, yet it is likely most women struggle to gain
41
42 autonomy and control over their decision-making and to manage their fears and
43
44 vulnerabilities for all cardiac conditions.
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49
50 This method did not allow pooling of results and comparison of data across studies
51
52
53 However, the analysis included an examination of how studies are related, or dissonant, by
54
55 comparing coding and themes as shown in Table 4. This enabled patterns to be discerned
56
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2
3 that may be translated to cardiac disease in pregnancy and potentially other rare and
4
5 chronic diseases in pregnancy. A thematic analysis may have also led to a loss of detail
6
7 particularly the unique contexts of women lives; however, efforts were made to maintain
8
9 this in the descriptive part of the analysis to retain the integrity of the original studies. The
10
11 exclusion of non-English papers may have resulted in an incomplete retrieval of research
12
13 studies. Our multi-disciplinary research team comprised of a social scientist, medical
14
15 ethicist, a cardiologist, obstetricians and a medical perinatal epidemiologist enabled a rich
16
17 and detailed yet complex account of the extracted data.
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23 *Conclusion*

24
25 Research into the experiences of women with cardiac disease in pregnancy is essential for
26
27 the development of evidence-based women-centred care to enable clinicians to better
28
29 respond to patient needs, values and preferences. This meta-synthesis revealed that there is
30
31 a need for tailored, responsive care and gendered models to guide shared decision-making
32
33 and empathetic counselling across the reproductive lifespan for women with cardiac
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35 disease.
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Acknowledgments

The authors would like to thank Sabina Belli for editing this paper.

Sources of Funding

This study was unfunded.

Conflict of interest

None

Author contributions

The study was conceived by EAS and EAS and AJD designed the study. YK and undertook the literature search and screening with assistance from AJD. YK, AJD and EAS critically appraised the papers. YK and AJD undertook the initial analysis with input from all authors (EAS, KL, MJP and WP). AJD wrote the manuscript, all authors edited and approved the final manuscript.

Data sharing statement

No additional data are available.

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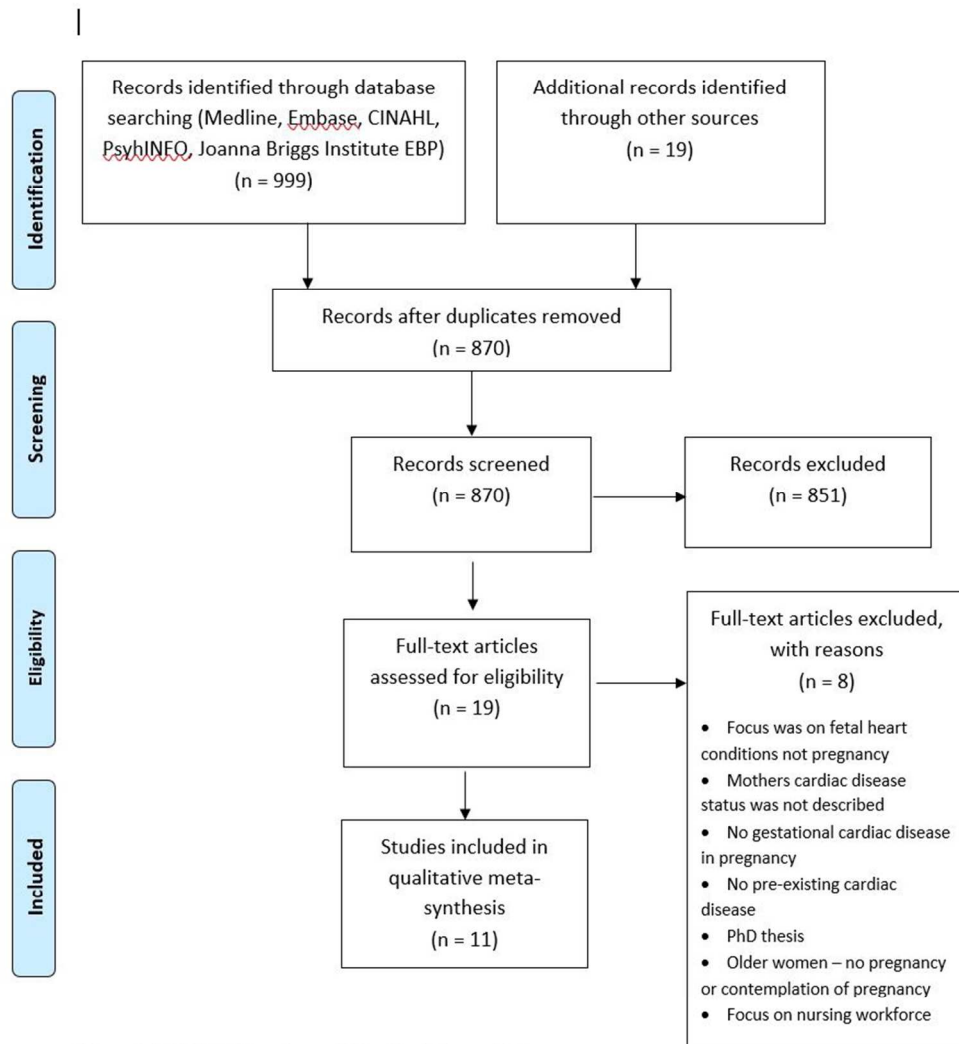


Figure1. PRISMA Flowchart of Cardiac Disease in Pregnancy

96x107mm (240 x 240 DPI)

Supplementary data-

Appendix 1: Full search strategy

Bibliographic Database	Search strategy
MEDLINE 1996 – 6 October 2016	<ol style="list-style-type: none"> 1 Cardiac disease.mp. or Heart Diseases 2 Postoperative Complications/ or Heart Transplantation/ or heart transplant.mp. or Heart Failure 3 Rheumatic heart disease.mp. or Rheumatic Heart Disease 4 Adult/ or Hypertension, Pulmonary/ or Heart Defects, Congenital/ or congenital heart disease.mp. or Cardiac Surgical Procedures/ 5 Hypertension/ or Cardiomyopathies/ or Cardiovascular Diseases/ or Arrhythmias, Cardiac/ or Heart Defects, Congenital/ or Heart Diseases/ or Cardiomyopathy, Hypertrophic/ or genetic cardiac disease.mp. 6 Arrhythmias, Cardiac/ or Myocardial Infarction/ or Atrial Fibrillation/ or chronic arrhythmia.mp. or Tachycardia, Supraventricular/ or Coronary Disease/ 7 1 or 2 or 3 or 4 or 5 or 6 8 Pregnancy Complications, Hematologic/ or Pregnancy, Unplanned/ or Pregnancy Maintenance/ or Pregnancy, High-Risk/ or Pregnancy, Unwanted/ or Pregnancy in Adolescence/ or Pregnancy, Multiple/ or Pregnancy Outcome/ or Pregnancy Complications/ or Pregnancy/ or Hypertension, Pregnancy-Induced/ or pregnancy.mp. or Pregnancy in Diabetics/ or Pregnancy, Abdominal/ or Pregnancy Complications, Cardiovascular/ 9 Pregnant women.mp. or Pregnant Women/ 10 Infant Mortality/ or Pregnancy/ or Maternal Health Services/ or Prenatal Care/ or Pregnancy Complications/ or antenatal care.mp. or Socioeconomic Factors/ 11 Perinatal care.mp. or Perinatal Care/ 12 birth.mp. or Parturition/ 13 postpartum.mp. or Postpartum Period 14 8 or 9 or 10 or 11 or 12 or 13 15 Decision making.mp. or Decision Making/ 16 Shared decision making.mp. 17 "Delivery of Health Care"/ or Decision Making/ or Physician-Patient Relations/ or Patient-Centered Care/ or patient centered care.mp. 18 15 or 16 or 17 19 midwives.mp. or Midwifery/ 20 General practitioner.mp. or General Practitioners/ 21 Primary physician.mp. 22 Obstetrics/ or obstetrician.mp. or Practice Patterns, Physicians'/

	<p>23 cardiologist.mp. 24 Family Practice/ or Allied Health Personnel/ or allied health professional.mp. 25 19 or 20 or 21 or 22 or 23 or 24 26 7 and 14 and 18 and 25</p>
<p>EMBASE: 1996 - 6 October 2016</p>	<p>1 cardiac disease.mp. 2 rheumatic heart disease.mp. or rheumatic heart disease/ 3 congenital heart disease.mp. orexp congenital heart disease/ 4 Arrhythmias.mp. or heart arrhythmia/ 5 1 and 2 and 3 and 4 6 pregnant women.mp. or pregnant woman/ 7 pregnancy Complications.mp. or pregnancy complication/ 8 infant Mortality.mp. or infant mortality/ 9 perinatal care.mp. or perinatal care/ 10 birth/ 11 postpartum pain/ or postpartum hemorrhage/ or postpartum.mp. 12 6 and 7 and 8 and 9 and 10 and 11 13 decision making.mp. or decision making/ 14 medical decision making/ or doctor patient relation/ or decision making/ or patient participation/ or informed consent/ or shared decision making.mp. or interpersonal communication/ 15 13 and 14 16 midwives.mp. or midwife/ 17 general practitioner.mp. or general practitioner/ 18 general practitioner/ or primary health care/ or general practice/ or primary physician.mp. 19 obstetrics/ or obstetrician/ or pregnancy/ or pregnancy complication/ 20 cardiologist/ or heart disease/ 21 family Practice.mp. or general practice/ 22 16 and 17 and 18 and 19 and 20 23 21 and 22 24 5 and 12 and 15 and 23 25 limit 24 to ("qualitative (maximizes sensitivity)" and English and article and last 20 years)</p>
<p>CINAHL (EBSCO) 1995 - 11 October 2016</p>	<p>S1" cardiac disease " S2 (MH "pregnancy") OR "pregnancy" S3 MH "decision making, patient") OR (MH "patient centered care") OR ""wom?n cent* care" OR "patient cent* care" OR "wom?n* experience" OR "shared decision making"" S4 S1 AND S2 AND S3</p>
<p>PsycINFO (EBSCO)</p>	<p>1. cardiac disease</p>

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1984 - 18 October 2016	<p>2. MH "Pregnancy") OR "pregnancy"</p> <p>3. (MH "Decision Making, Patient") OR (MH "Patient Centered Care") OR ""wom?n cent* care" OR "patient cent* care" OR "wom?n* experience" OR "shared decision making""</p> <p>4. 1 AND 2 AND 3</p>
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Section/topic	#	Checklist item	Reported on page #
TITLE			
A qualitative meta-synthesis review of the experiences of women with cardiac disease who have been, are pregnant or considering pregnancy	1	Identify the report as a systematic review, meta-analysis, or both. – meta-synthesis	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	3-4
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	5-6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. – N/A	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. – Appendix 1.	32-34
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	8-9

Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	8-9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	9
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	9
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	9
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	27
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	9
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	10-12
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	13-14
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	16-17
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	16, 18-27

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4	Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	27
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6	Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	27-28
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8	FUNDING			
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10	Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	28
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BMJ Open

Experiences of women with cardiac disease in pregnancy: A systematic review and meta-synthesis

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-022755.R1
Article Type:	Research
Date Submitted by the Author:	03-Jul-2018
Complete List of Authors:	Dawson, Angela; University of Technology, Sydney, Australian Centre for Public and Population Health Research Krastev , Yordanka; University of Technology, Sydney, Australian Centre for Public and Population Health Research Parsonage, William; Royal Brisbane and Women's Hospital, ; Queensland University of Technology, Peek, Michael; Australian National University, ANU Medical School Lust, Karin; University of Queensland, Women's and Newborn Services, Royal Brisbane and Women's Hospital Sullivan, Elizabeth; University of Technology Sydney Faculty of Health, Australian Centre for Public and Population Health Research
Primary Subject Heading:	Obstetrics and gynaecology
Secondary Subject Heading:	Cardiovascular medicine
Keywords:	Pregnancy, cardiac disease, women centered care, shared decision-making, qualitative meta-synthesis

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Manuscripts

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3 **Experiences of women with cardiac disease in pregnancy: A systematic review and meta-**
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5 **synthesis**
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ABSTRACT

Objective

Cardiac disease in pregnancy is a leading cause of maternal death in high-income countries. Evidence-based guidelines to assist in planning and managing the healthcare of affected women is lacking. The objective of this research was to produce the first qualitative meta-synthesis of the experiences of pregnant women with existing or acquired cardiac disease to inform improved healthcare services.

Method

We conducted a systematic search of peer-reviewed publications in five databases to investigate the decision-making processes, supportive strategies and healthcare experiences of pregnant women with existing or acquired cardiac disease, or of affected women contemplating pregnancy. Identified publications were screened for duplication and eligibility against selection criteria, following PRISMA guidelines. We then undertook a thematic analysis of the data relating to women's experiences extracted from each publication to inform new healthcare practices and communication.

Results

Eleven studies from six countries were included in our meta-synthesis. Four themes were revealed. Women with congenital and acquired heart disease identified situations where they had either taken charge of decision-making, lacked control, or experienced emotional uncertainty when making decisions. Some women were risk aware and determined to take care of themselves in pregnancy while others downplayed the risks. Women with heart disease acknowledged the importance of specific social support measures during pregnancy and after child birth, and reported a spectrum of healthcare experiences.

Conclusions

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3 There is a lack of integrated and tailored healthcare services and information for women
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5 with cardiac disease in pregnancy. The experiences of women synthesised in this research
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7 has the potential to inform new evidence-based guidelines to support the decision-making
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9 needs of women with cardiac disease in pregnancy. Shared decision-making must consider
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11 communication across the clinical team. However, coordinated care is challenging due to
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13 the different specialists involved and the limited clinical evidence concerning effective
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15 approaches to managing such complex care.
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21 **Keywords:** Pregnancy, cardiac disease, women-centred care, shared decision-making,
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23 qualitative meta-synthesis.
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26 27 28 **Article Summary**

29 30 **Strengths and limitations of this study**

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32 • This is the first meta-synthesis of qualitative research that investigated the
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34 experiences of pregnant women with a spectrum of cardiac disease.
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36 • The small number of studies in this synthesis demonstrated the paucity of qualitative
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38 research in this area, particularly the voices of pregnant women with genetic
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40 conditions.
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44 • The thematic analysis enabled patterns to be discerned that could be translated to
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46 cardiac disease in pregnancy and potentially other rare and chronic diseases in
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48 pregnancy.
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52 • Our multi-disciplinary research team enabled a rich and detailed yet complex
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54 account of the extracted data.
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INTRODUCTION

Cardiac disease in pregnancy is a leading cause of maternal death in the developed world. In the United States, pregnancy related deaths due to cardiovascular disease were ranked as the leading category of death from 2011 to 2013 at 15.5%¹. In the United Kingdom, the rate of maternal deaths associated with cardiac disease more than doubled from 1.0 in 1985 to 2.3 per 100,000 maternities in 2008². In Australia, cardiac disease in pregnancy has been the leading cause of indirect maternal deaths for almost 50 years^{3,4}, and a common cause of late maternal death^{4,5}.

Cardiac disease in pregnancy constitutes a broad spectrum of conditions, including congenital heart diseases (e.g. ventricular septal defect, transposition of the great vessels), genetic heart diseases (e.g. hypertrophic cardiomyopathy, long QT syndrome, Brugada syndrome), chronic arrhythmia conditions (e.g. Wolff Parkinson White syndrome), as well as heart diseases acquired before or during pregnancy (e.g. rheumatic heart disease, ischemic heart disease, peripartum cardiomyopathy). Heart transplants can also affect pregnancy outcomes.

Cardiac disease in pregnancy is associated with high rates of morbidity and hospitalisation: 15% of women in Europe have been admitted for cardiac indications during pregnancy⁶. Approximately one in four women with cardiac disease in pregnancy are hospitalised during pregnancy, and overall cardiac disease in pregnancy is associated with the increased likelihood of eclampsia, caesarean birth and postpartum haemorrhage⁶. For the baby, there is an increased likelihood of stillbirth, preterm birth and acquired congenital disease⁶. The European Registry of Pregnancy and Cardiac Disease has reported significant adverse

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3 perinatal outcomes for both mother and baby, most notably a maternal mortality rate of
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5 1%, which is more than 100-times the rate for women without cardiac disease.
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10 Confidential death enquiry data from the UK suggest there are an increasing number of
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12 women who die from the combination of pregnancy and cardiac disease ². There are several
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14 possible explanations for this observation, including the improved survival (~90%) of
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16 children with congenital heart disease to adulthood, increased awareness and diagnosis of
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18 genetic conditions, lifestyle factors (e.g. obesity), and older maternal age associated with
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20 ischemic heart disease ⁷⁻⁹.
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26 Many women with cardiac disease have been found to have high rates of unintended
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28 pregnancies that may reflect issues concerning the attitudes of healthcare professionals
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30 with providing counselling, and gaps in women's contraceptive knowledge and availability of
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32 decision-making support ^{10 11}. Despite clinical available guidelines ¹²⁻¹⁴, limited knowledge
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34 exists regarding the healthcare, support and decision-making experiences of women with
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36 cardiac disease who are pregnant, or contemplating pregnancy. Insights into women's
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38 experiences of planning and undergoing pregnancy including their perceptions and
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40 satisfaction are critical to the provision of health services, care and information.
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46 This paper aims to synthesise qualitative healthcare evidence to deliver new insights to best
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48 support decision-making for women with cardiac disease and for healthcare professionals to
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50 improve their quality of cardiac care from pre-conception planning to the postnatal period.
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53 54 55 **METHODS**

Data sources and search strategy

We undertook a qualitative systematic review of the literature and conducted a meta-analysis following methods outlined by Thomas and Harden¹⁵ to understand the healthcare experiences of pregnant women or women contemplating pregnancy with existing or acquired cardiac disease, in order to gain insights into their resilience including coping strategies.

We used the PRISMA statement (Fig. 1) with a cut-off date of 2016. We searched the literature available in five on-line, bibliographic databases: CINAHL Plus (1995–October 2016); Embase (1996–October 2016); Ovid MEDLINE (1996–October 2016); PsycINFO (1984–October 2016) and the Joanna Briggs Institute Evidence Based Practice Database (1996–October 2016). Boolean operators (and, or, not) were used to refine our search with the following keywords: cardiac disease, pregnancy, pregnant women, decision-making, and shared decision-making. Publications that met our selection criteria (Table 1) were further analysed. We also searched for publications in Google Scholar and manually from the reference lists of key papers that identified an additional 19 relevant publications. See Appendix 1 (supplementary file) for details of the bibliographic search strategy.

Figure1. PRISMA Flowchart of Cardiac Disease in Pregnancy

Table 1. Inclusion and exclusion criteria used to identify publications that involved women with cardiac disease in pregnancy

Inclusion Criteria	Exclusion Criteria
The experiences of women of reproductive age with existing or acquired cardiac disease in pregnancy who were, or had been pregnant, or who had contemplated pregnancy (including preconception, and prenatal, intrapartum, perinatal and postnatal periods)	Women with cardiac disease who were not of reproductive age or who had not been or contemplated pregnancy
Qualitative studies	Quantitative studies
Mixed methods design with a qualitative component	Clinical studies of cardiac disease in pregnancy
Published in the English language	Non-English articles

Quality assessment and data extraction

Nineteen potentially relevant publications were identified. Of these, eight were excluded because they were either irrelevant or not peer-reviewed (e.g. PhD thesis). Six qualitative publications and the qualitative components of five mixed methods publications were appraised using the Critical Appraisal Skills Program (CASP) qualitative checklist¹⁶ by two authors (AD and YK). Each paper was independently assessed using a table with ten CASP questions that analysed the data sampling, collection and analysis processes and the coherence of the paradigm underpinning the study involving the fit between the data gathered and the conceptual work of analysis and interpretation. Despite the methodological limitations of some papers, including gaps in the discussion of reflexivity and credibility, all 11 papers were included in the meta-synthesis as it was deemed that their strengths outweighed these issues. Data from the findings sections of each publication, that detailed the preconception planning and pregnancy experiences of women with cardiac

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3 disease, were extracted for further analysis. This included direct quotes and text describing
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5 related findings.
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9 10 **Data analysis**

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12 The extracted text was coded 'line-by-line' by two authors (AD and YK) and then descriptive
13
14 categories were developed that aligned with the original studies. The concepts from the
15
16 descriptive categories were grouped into themes and sub themes and conceptual links
17
18 among themes were identified. Tables were used for this process. Emerging descriptor texts
19
20 were highlighted in different colours in each study in each paper. These descriptors were
21
22 then compared across papers and similar descriptors were synthesised into one table. This
23
24 led to the conflation of descriptive themes and the development of emergent categories
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26 whose meaning was refined in order to answer the research questions and address the aim
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28 of the study¹⁷.
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35 **Patient and public involvement**

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37 Qualitative patient data was the focus of this synthesis; however, patients and the public
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39 were not involved in the design of the study or analysis of the data.
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RESULTS

A summary of the methodology and findings of the 11 studies used in this study is given in

Table 2. The studies were conducted across six countries: The United States of America

(n=5), Australia (n=2), Sweden, (n=2), Canada (n=1), Norway (n=1) and Belgium (n=1). Six

studies comprised qualitative designs¹⁸⁻²³ and five used mixed methods²⁴⁻²⁸ (see Table 3).

There were a total of 383 women participants with the following conditions: congenital

heart disease (n = 81), peripartum cardiomyopathy (PPCM; n = 298), and Long QT syndrome

see Table 3; n = 4).

Table 2. Summary of the methodology and data of the 11 publications used in this study

Publication	Method	Aim	Findings
Andersen et al. 2008 ¹⁸	Qualitative: in-depth, face-to-face interviews	<ul style="list-style-type: none"> To investigate psychosocial aspects of living with Long QT Syndrome(LQTS) To identify the daily challenges and coping strategies of LQTS patients To describe the experience of LQTS patients with healthcare services 	<ul style="list-style-type: none"> LQTS patients were concerned that the condition would be inherited by their children and grandchildren. LQTS patients favoured early genetic testing for LGTS, and the provision of information about LQTS in children presented early and gradually.
Claessens et al.2005 ¹⁹	Qualitative: unstructured, in-depth interviews	<ul style="list-style-type: none"> To explore the lived experiences of adult congenital heart disease patients 	<ul style="list-style-type: none"> The central theme of the patients' lived experiences was "feeling different". Patients struggled constantly with themselves and with their environment to be accepted as normal.
Dekker et al. 2016 ²²	Publicly available narratives from three online support groups	<ul style="list-style-type: none"> To describe the experience of women diagnosed with Peripartum Cardiomyopathy (PPCM) 	<ul style="list-style-type: none"> Nearly 40% of women felt that they were dismissed by health-care providers. Women had difficulty caring for their newborns during the postnatal period, and they struggled with the medical advice they received to not conceive again.

Publication	Methods	Aim	Findings
Gantt 1992 ²¹	Qualitative: unstructured face to face interviews; Grounded-Theory	<ul style="list-style-type: none"> To generate an understanding of, and theories about, the lives of women with congenital heart disease 	<ul style="list-style-type: none"> Lack of information related to women's bodies and reproductive issues ("growing up female"). Over involvement of mothers and healthcare professionals in the affairs of the child's and woman's body, resulting in decreased ownership of the body by the woman ("living against the body"). Poor self-esteem, self-concept, and body image ("growing up heartsick"). A need for various types of counselling for women with congenital heart disease was identified.
Gantt 2002 ²⁰	Qualitative: descriptive with unstructured interviews	<ul style="list-style-type: none"> To study the effect of congenital heart diseases on the mother–daughter relationship 	<ul style="list-style-type: none"> Overriding theme of the study was normalising in the face of chronic illness, with a tendency by the mothers and daughters to focus on their lives instead of their relationship with one another.
Hess et al. 2010 ²⁶	Descriptive: a survey of open-ended and Likert-type questions	<ul style="list-style-type: none"> To determine the benefits of participation in the on-line support group for peripartum cardiomyopathy, based on a survey of active members of the group 	<ul style="list-style-type: none"> One of the most important issues facing women with peripartum cardiomyopathy is future childbearing. The benefits of participation in the online support group included obtaining and sharing information, exchanging stories, being understood by other women and reassurance.
Hess et al. 2012 ²⁷	Mixed method: analysis of social media postings made by 156 people	<ul style="list-style-type: none"> To describe the contents of postings made on the My Space® peripartum cardiomyopathy support group website by women with peripartum cardiomyopathy 	<ul style="list-style-type: none"> The subject of pregnancy subsequent to the diagnosis of peripartum cardiomyopathy was mentioned 102 times (amongst 247 posts), making it an issue that was foremost in the minds of many women.

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Publication	Methods	Aim	Findings
Ngu et al. 2014 ²⁵	Mixed method: retrospective and descriptive	<ul style="list-style-type: none"> To assess the perceptions of women with congenital heart disease regarding the severity of their cardiac abnormality and its implications in pregnancy, and whether their motivations to conceive were similar to those of women without congenital heart disease 	<ul style="list-style-type: none"> The personal experience of women, who successfully lived with their heart condition, influenced their perception of the pregnancy risks. Women with congenital heart disease were concerned about the health risks associated with their congenital heart disease and that of their child.
Ngu et al. 2014 ²⁴	Mixed method: Case studies	<ul style="list-style-type: none"> To understand the motivations of women with congenital heart disease to bear children, and to assess if there were any differences between the cohort with low risk and those with high risk heart disease 	<ul style="list-style-type: none"> Women with high risk (moderate to severe) congenital heart disease appeared to have similar motivations for conceiving as women with low-risk (mild) congenital heart disease. Their drive for motherhood appeared to be stronger than their drive for self-care.
Patel, Berg et al 2016 ²⁸	Mixed method: qualitative face-to-face and telephone interviews; review of medical records	<ul style="list-style-type: none"> To explore and describe the experiences of symptoms in peripartum cardiomyopathy in women 	<ul style="list-style-type: none"> A sense of being caught in a spider web consisting of the invasion of the body by experienced symptoms and a feeling of helplessness.
Patel, Schaufelberge et al. 2016 ²³	Qualitative: unstructured interviews	<ul style="list-style-type: none"> To explore the healthcare experience of women during their diagnosis with peripartum cardiomyopathy 	<ul style="list-style-type: none"> The main theme was "Exacerbated Suffering" expressed in three subthemes: "not being cared about", "not being cared for", and "not feeling secure".

Table 3. Summary of the conditions, participants and study locations and of the 11 publications used in this review

Publication	Condition		Country	Number of participants	Age range (years)
	Congenital heart disease	Other acquired heart disease			
Andersen et al. 2008 ¹⁸	Long QT Syndrome		Norway	Adults (n = 7): 4 women, 3 men	23–76 (n = 7)
Claessens et al. 2005 ¹⁹	Moderate or severe heart defects, such as Tetralogy of Fallot, univentricular heart, VSD and aortic valve stenosis, transposition of the great arteries		Belgium	Adult patients (n = 12): 6 women; 6 men	25–40 (n = 12)
Dekker et al. 2016 ²²		Peripartum Cardiomyopathy	USA	Adult women (n = 92): 1 st pregnancy (n = 49) 2 nd pregnancy (n = 24) 3 rd pregnancy (n = 10) >4 th higher pregnancy (n = 8) unreported (n = 1)	17–41 (n = 92)
Gantt 1992 ²¹	Transposition of the great vessels (TOGV), pulmonary atresia, atrial septal defect (ASD), double outlet right ventricle, pulmonary stenosis, truncus arteriosus, coarctation of the aorta		USA	Adolescent, young adults (n = 13)	13–15 (n = 3) 16–18 (n = 4) 19–21 (n = 3) 22–28 (n = 3)
Gantt 2002 ²⁰	One woman with childhood rheumatic fever; one adolescent woman had a heart murmur only; all other women had congenital heart diseases of varying types and severity that had been surgically repaired or palliated		USA	Adults and children (n = 22): 11 mothers and 11 daughters	30–60 9-18

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Publication	Condition		Country	Number of participants	Age range (years)
	Congenital heart disease	Other acquired heart disease			
Hess et al. 2010 ²⁶		Peripartum Cardiomyopathy	USA	Adult women (n = 12): 7 women did not have other children prior to the diagnosis	19–34 (n = 12)
Hess et al. 2012 ²⁷		Peripartum Cardiomyopathy	USA	Adults (n = 156): 148 (95%) women with PPCM 8 (5%) husbands, mothers, sisters and grandmothers.	~27 (n = 156)
Ngu et al. 2014 ²⁵	Mild: pulmonary atresia, moderately large VSD, transposition of the great vessels, coarctation of aorta, bicuspid aortic valve, Ebstein’s anomaly of tricuspid valve Moderate: Tetralogy of Fallot, mitral valve dysplasia, sub aortic stenosis Severe: VSD; aortic valve stenosis, double outlet right ventricle		Australia	Women with (n = 20) or without (n = 20) CHD aged >18 years, who had ≥1 successful pregnancy.	32.6 ± 5.3 Women with congenital heart disease 33.9 ± 5.2 Women without congenital heart disease

For peer review only

Publication	Condition		Country	Number of participants	Age range (years)
	Congenital heart disease	Other acquired heart disease			
Ngu et al. 2014 ²⁴	Mild: pulmonary atresia, moderately large VSD, transposition of the great vessels, coarctation of the aorta, bicuspid aortic valve, Ebstein's anomaly of tricuspid valve Moderate: Tetralogy of Fallot,; mitral valve dysplasia, sub aortic stenosis Severe: VSD; aortic valve stenosis; double outlet right ventricle		Australia	Women with mild CHD (n = 10) with: 1 child (n = 4) 2 children (n = 4) 3 children (n = 2). Women with moderate to severe CHD (n = 10) with: 1 child (n = 5); 2 children (n = 3); 3 children (n = 2).	35.8 ± 5.9 (n = 10): women with mild – CHD-mean age 28.9 ± 3.5 (n = 10): women with moderate to severe CHD
Patel, Berg et al. 2016 ²⁸		Peripartum Cardiomyopathy	Sweden	Adult Women (n = 19)	28–46 (n = 19)*
Patel, Schaufelberg et al. 2016 ²³		Peripartum Cardiomyopathy	Sweden	Women (n = 19)	28–46 (n = 19)*

*Separate studies drawing upon data from the same cohort of women

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Four themes and seven sub-themes emerged from our meta-analysis and are summarised in Table 4 and described in more detail below.

For peer review only

Table 4. Frequency of themes in women with cardiac disease in pregnancy identified in the literature

Publication	Themes:	Women's autonomy and control				Self-care and risk awareness in pregnancy	Social support for decision-making	Health care experiences		
		Taking charge of decision-making	Lack of control	Emotional uncertainty of decision-making	Helplessness, fear and vulnerability			Health information needs	Responsive care	Listening to women
Congenital heart disease										
Andersen et al 2008 ¹⁸	✓	✓	✓	✓	✓	✓	✓			
Claessens et al. 2005 ¹⁹	✓	✓	✓	✓						
Gantt 2002 ²⁰	✓			✓	✓					
Gantt 1992 ²¹	✓	✓			✓			✓		✓
Ngu et al. 2014 ²⁴					✓	✓			✓	
Ngu et al. 2014 ²⁵	✓				✓	✓				
Other acquired heart disease										
Dekker et al. 2016 ²²			✓	✓	✓			✓	✓	✓
Hess et al. 2010 ²⁶	✓					✓	✓	✓		✓
Hess et al. 2012 ²⁷	✓						✓			✓
Patel, Berg et al. 2016 ²⁸				✓	✓					
Patel, Schaufelberge et al. 2016 ²³					✓				✓	✓

Women's autonomy and control

Taking charge of decision-making

Some women expressed their determination to take control and make their own decisions regarding their pregnancies. One woman was resolute to try to fall pregnant and if unsuccessful wanted to consider other options: "I want to give birth to at least one child. I want to have the opportunity to do that, then later I can adopt ..." ¹⁸. Another woman became pregnant two months after her diagnosis of heart disease and described being "told to terminate her pregnancy" but she "refused" ²⁷. Another woman felt she "had lived a good life" and her disease "could not be considered a reason for terminating a pregnancy" ¹⁸. The positive thinking that "life isn't over just because you have peripartum cardiomyopathy" and the possibility of having more children was a key factor driving the decision of women who went through another pregnancy and "received a beautiful little girl in exchange" ²⁶.

The trust that women had in their clinicians and their experiences of successfully adapting to their congenital cardiac disease by developing coping mechanisms, played a role in their desire to make their own decisions and proceed with their pregnancies ²⁵. Some women felt that they had to take responsibility not only for their own health, but also for that of future generations. These women undertook genetic testing as early as possible ¹⁸ to prevent giving birth to a child with congenital heart disease ²¹.

Women desired to take control and live a "normal life" ^{20 24}, participate in social activities and "fit in" ²¹. This often stemmed from childhood experiences of being excluded and "feeling different" ²¹. For some women, this motivated them to make their own decisions

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3 and to take on new and different activities as a means of coping: "I do these things just to
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5 challenge those boundaries, limitations" ¹⁹.
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8 9 *A lack of control*

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11 In contrast, a lack of autonomy and control was noted by women in relation to pregnancy
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13 decision-making. Some women believed that someone else would decide whether they
14
15 should become pregnant in response to being "told right from the beginning not to have any
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17 more children" ²². Another woman felt that she had no choice and could not take the risk
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19 and have her family shoulder the burden of another episode of heart failure ²¹. Others
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21 described feeling how social pressure and the judgment of others interfered with their
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23 decision to have more children: "you're not supposed to get pregnant when you have
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25 congenital heart disease" ²¹. Another woman, who already had a child diagnosed with heart
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27 condition, feared being perceived as "selfish" ¹⁸.
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35 For some of the women, their heart disease defined and dominated their decision-making
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37 ¹⁸. One woman talked of how everything in her life "came down to the heart" ²¹. While
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39 another described the tension the control of their disease had over them, and their own
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41 autonomy to make decisions, including those about pregnancy: "I do make plans and that
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43 sort of thing, but I don't dare to carry them out. Now I understand that ...I must start
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45 something independently ...but I'm scared" ¹⁹. A lack of autonomy and control was
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47 discussed by women in relation to financial hardship. Some women said that they had
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49 registered for disability payments after their diagnosis and were concerned that they would
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51 not be able to work after giving birth and contribute to the household income due to the
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3 impact the pregnancy would have on their physical and mental health. As a result, these
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5 women felt they would be financially dependent upon others ²².
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8 9 *The emotional uncertainty of decision-making*

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11 In three studies, women described the emotional uncertainty of their pre-conception
12
13 decision-making in highly emotional terms, where they were at a loss regarding what to do
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15 ^{18 19}. One woman asked 'Is it worth it having a baby?' ²⁸. Women expressed feelings of being
16
17 depressed, devastated, experiencing "emotional torture", feeling "hysterical" when they
18
19 were diagnosed with cardiac disease and advised by their doctors against future
20
21 pregnancies ²². These circumstances required them to re-think their situation ²². Several
22
23 women described the decisions regarding pregnancy and childbirth as extremely difficult for
24
25 them ¹⁸ due to uncertainty regarding the progression and prognosis of their disease ¹⁹.
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32 33 *Helplessness, fear and vulnerability*

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35 The feeling of helplessness and loss of control in relation to the development of cardiac
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37 disease symptoms both during pregnancy, birth and postpartum was expressed by one
38
39 woman as like "being caught in a spider web" ²⁸, or being trapped by their condition and
40
41 fearful about future pregnancies ²⁰. Another woman described being pregnant as a
42
43 "constant struggle between hope and helplessness" ²⁸. There was a mix of physical and
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45 emotional symptoms when women described the suffering of their own illness and the
46
47 inability to take care of their newborn baby ^{22 23}.
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53 Women feared dying. They were deeply concerned that they would not survive the
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55 pregnancy and that they would leave their child motherless, ^{21 24 25} or be left disabled and
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3 unable to care for their newborn²⁴. They were worried about passing on heart disease to
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5 their unborn baby^{18 24}, giving birth to a baby with a heart abnormality,^{21 24} and the effect
6
7 that medications might have on their baby²¹. These fears deeply affected women and some
8
9 continued to relive the distress brought on by the diagnosis of cardiac disease in pregnancy
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11 through flashbacks, years after the birth of their child²³.
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16 17 **Self-care and risk awareness in pregnancy**

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19 Risk awareness and desire for motherhood were discussed in four of the papers^{18 24 25 27}. In
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21 a study by Andersen et al.¹⁸ women with Long QT syndrome reported being frustrated not
22
23 to know how much danger to their health a pregnancy might impose. They felt that if they
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25 took the risk to become pregnant, the decision was theirs.
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31 For another group of women with congenital heart disease, the determination to have a
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33 child was so strong, that it outweighed self-care considerations. Despite being aware of the
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35 complications during pregnancy, 10 of the 20 women in the study perceived their disease to
36
37 be less severe than that reported by their clinicians. These women therefore down played
38
39 the seriousness of their condition that was found to be related to a reliance on the care of
40
41 their health professionals, and a belief that medical and surgical care would result in a
42
43 successful pregnancy and birth outcome. This distorted view of their condition was also
44
45 linked to their quality of life which they felt was good²⁴.
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51 52 **Social support for decision-making**

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54 A feeling of empowerment and hope provided through social support was clearly
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56 demonstrated in several publications analysed in this study. Women using an online support
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3 said, “It is beneficial to know that you are not alone”²⁶, “friendly, open arms” that “gave me
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5 hope”,²⁶ and “there is always hope”²⁷. Some women shared the positive feeling of being
6
7 able to talk to someone who could understand them without judgment and to share
8
9 experiences. Women found peer-education to be an important part of managing their life
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11 and living with heart failure²⁶. Another woman described the distress of having to face her
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13 pregnancy decision-making alone, as she lacked support from her family, who did not want
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15 her to take any risks¹⁸.
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21 **Health care experiences**

22 *Health information needs*

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25 Our study revealed gaps in the understanding of women’s health information knowledge or
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27 needs by clinicians. Several women felt that they had received inadequate information from
28
29 clinicians. Only six of the participants in one study had information about contraception and
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31 its relationship to their heart disease²¹. One woman stated that she was “shocked” that
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33 none of her clinicians had discussed the severity of her condition with her: “I thought I was
34
35 completely fine. I didn’t know I wasn’t supposed to have any more kids”²⁶. The need for
36
37 appropriate information delivery and counselling was highlighted by one woman who
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39 recounted the time of extreme panic when her doctor delivered her diagnosis: “With no
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41 family present, he told me that I might need a heart transplant and that I was finished being
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43 pregnant”²².
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51 *Responsive care*

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53 Many women felt that they had received supportive care from their healthcare team, were
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55 grateful and praised the skills and responsiveness of their clinicians. One woman expressed
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3 this by stating that the “world's elite team was there for me during the labour”²³. Another
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5 group of 13 women shared how grateful they were to the nurses who brought their
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7 newborn babies to the intensive care unit where they were staying, and recognised the
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9 separation concerns²². Women also reported feeling “secure” when provided with the
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11 phone number of a cardiac nurse or cardiologist to call if they were worried or had
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13 questions. Women valued check-ups as these gave them “hope”²³. Women trusted their
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15 clinicians and perceived them to be compassionate professionals who would carefully
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17 monitor and support them throughout their pregnancy²⁴.
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23 *Listening to women*

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25 Women commented on situations where clinicians had overly relied on the results of
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27 objective tests and careful monitoring throughout their pregnancy to manage their
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29 healthcare, rather than listening to them and taking their experiences and feelings into
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31 consideration²³. Some women reported that their voices were dismissed: “they didn’t seem
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33 to care.”²², “they did not listen to me”, and “did not respect my wish.”²³. As a result,
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35 women felt ignored, or misjudged, which caused sadness, insecurity and disappointment in
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37 the service provided by their healthcare professionals. Women expressed feeling rejected
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39 by clinicians and felt that they were treated “like a drug addict, “like a pile of garbage”²³,
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41 “like a baby”²¹. One woman suggested that clinicians learn more about the symptoms of
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43 their condition and take the complaints of their patients seriously²⁶.
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51 *Healthcare facilities and professionals*

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53 There was a paucity of information in the literature regarding the healthcare centres and
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55 the specialist skills of their providers to support the needs of women with heart diseases. In
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3 Australia, women with congenital heart disease were reported to have received care from
4 cardiologists in a public tertiary hospital²⁴ and in private clinics²⁵, in south eastern USA they
5 received care at a large tertiary care centre²¹, and in Norway, they received care at a
6 university hospital¹⁸. Women with congenital heart disease had also been recruited through
7 an audit of records at a hospital department of paediatric and congenital cardiology in
8 Belgium¹⁹ and in another US study, by private paediatricians²⁰. Women only referred to
9 care they had received from both cardiologists and obstetricians in the Australian studies.
10 Although women in the American and Norwegian studies referred generically to their
11 “doctors” or “health providers” and nurses were noted in the paper from Belgium, less
12 information was available regarding the health facilities and providers of women with other
13 acquired heart disease from the US^{22 26 27} and Sweden^{28 23}. However, women in all studies,
14 except in Hess et al.²⁷, referred to cardiologists, obstetricians, nurses^{22 23}, midwives^{28 23} and
15 emergency department staff^{27 23} as their healthcare providers. It is difficult to draw
16 conclusions from the findings of this study concerning the different healthcare experiences
17 of women according to their providers and the facilities where they received care. While
18 women with acquired heart disease were more likely to mention the care of cardiologists
19 and obstetricians, as well as describe being listened to by their providers, such descriptions
20 were not available in the corresponding papers that described women with congenital heart
21 disease^{24 25}.

DISCUSSION

22 This paper reports the first meta-synthesis of qualitative research that investigated the
23 experiences of pregnant women with a spectrum of cardiac disease. It provided insight into
24 the continuum of preconception, pregnancy and parenting decision-making of these women

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3 and provided evidence to inform new healthcare practices and communication for cardiac
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5 care in women with heart disease. It detailed their struggles with gaining autonomy and
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7 control over their decision-making, how presented challenges to self-care during pregnancy
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9 and how impacted their daily lives. The level of autonomy and control was the most
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11 prevalent theme that came across all cardiac conditions investigated reflecting the need for
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13 women centred care.
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18 Our approach did not enable pooling of results and comparison of data across studies.
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20 However, our analysis explained how the studies were related, or dissonant, and compared
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22 coding and themes (see Table 4). This enabled patterns to be discerned that could be
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24 translated into cardiac disease in pregnancy and potentially other rare and chronic diseases
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26 in pregnancy. It is possible that our thematic analysis may have led to a loss of detail,
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28 particularly in relation to the unique contexts of women lives; however, efforts were made
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30 to maintain this in the descriptive part of the analysis to retain the integrity of the original
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32 studies. The exclusion of non-English papers may have resulted in an incomplete retrieval of
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34 research studies.
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42 **Women's autonomy and control**

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44 In five of the studies in our meta-synthesis, women identified a lack of understanding of,
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46 and attention to their existing knowledge by clinicians, as well as their self-reported health
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48 status and health needs as barriers to satisfactory care^{21-23 26 27}. While suggestions were
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50 made about how shared decision-making could be implemented into cardiovascular care²⁹
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53³⁰, and translated into practice in to national programs such as the Million Hearts®
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3 initiative^{31 32}, a gendered approach was not considered, nor examined in the unique context
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5 of various cardiac conditions in pregnancy.
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10 Clinicians could be better supported to facilitate a woman's active role in decision-making at
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12 the point of care by using tailored tools, particularly where a woman's self-care may be
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14 affected by downplaying their cardiac disease as found in two studies in the meta-synthesis
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16 ^{24 25}. In these cases, gendered tools that incorporate collaborative deliberation ³³ or
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18 conversations between women and clinicians, could have been useful.
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23 The Elwyn et al. 2013 "Talk model"³⁴ provides a useful conceptual framework for shared
24
25 decision-making that enables measurement across four components to facilitate effective
26
27 communication and its on-going evaluation between a women and her clinician. However,
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29 women also have a responsibility to contribute to charting a clear path through decision-
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31 making by identifying barriers and solutions to their implementation ³⁵. Even though the
32
33 Elwyn Talk Model provides a practical way forward for clinicians and women, it does not
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35 consider the steps or processes required for implementation including buy-in at the
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37 individual clinician and practice level through guidelines and consensus statements,
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39 integration into the workflow and evaluation,²⁹ particularly in the context of cardiac disease
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41 in pregnancy ¹².
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49 Although the voices of pregnant women with genetic conditions and/or from low, lower-
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51 middle and upper-middle income high-income countries as per the World Bank Atlas
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53 definition³⁶, were absent from the literature it is likely that they too would struggle to gain
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3 autonomy and control over their decision-making and to manage their fears and
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5 vulnerabilities for all cardiac conditions.
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8 9 **Self-care and risk awareness in pregnancy**

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11 Consistent with previously published reports³⁷⁻⁴⁰, our study revealed little insight into pre-
12
13 conception counselling and the advice clinicians provided concerning contraception for
14
15 women with existing cardiac disease or after a pregnancy, when cardiac disease was
16
17 diagnosed. In one study, less than 50% of women with cardiac disease had received any
18
19 counselling³⁹. We found that the timing of a woman's diagnosis of cardiac disease and
20
21 hence her experience, was different depending on the type of heart condition. Most of
22
23 those with congenital heart disease would have been expected to have knowledge of their
24
25 conditions, and ideally would have had pre-conception counselling. However, for those with
26
27 peripartum cardiomyopathy, the diagnosis may have occurred late in pregnancy, meaning
28
29 that some women would have entered pregnancy without cardiac disease and experienced
30
31 a very different pregnancy until diagnosed. However, many women with peripartum
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33 cardiomyopathy present post-partum⁴¹ and therefore these women's counselling needs
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35 would take into consideration subsequent pregnancies.
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44 Miner et al 2004 emphasised the importance of including contraceptive counselling early in
45
46 adolescence on an "on-going basis"³⁸. Furthermore, the American Heart Association and
47
48 others provide recommendations regarding prenatal counselling for women and their
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50 families with heart disease, as well as counselling in relation to the expectant child that
51
52 takes into consideration feeding and growth issues, quality of life and long-term care, family
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54 stressors, and foetal cardiac interventions^{12 42}.
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Social support for decision-making

The health benefits of social support for pregnant women from their partner, family, friends and those who have experienced similar circumstances are well known⁴³ and a significant predictor of health-related quality of life. Other authors have highlighted the importance of peer mentoring for pregnant women with defined health needs to allay fear and anxiety, particularly for women with spinal cord injuries^{44 45} and patients with cardiovascular disease⁴⁶. Women in two papers in our study^{26 27} found that on-line blogs related to their disease were helpful. Other studies found on-line forums to be supportive for other pregnant women with rare or life-threatening conditions in pregnancy⁴⁷.

Health care experiences

Decision-making tools for healthcare can increase patient participation and improve accurate risk perceptions^{48 49}. For women with heart disease, our recommendation is that women should be engaged in the design of these decision-making tools in consultation with healthcare providers and that an effective communications strategy is implemented that links the opinions of cardiologists, obstetricians, maternal foetal medicine specialists, obstetric physicians and anaesthetists, intensivists, midwives and cardiac nurses⁵⁰ to optimise patient care. This strategy would provide a comprehensive support tool that would console women, allay their fears, and build their confidence and resilience through coping and self-care strategies. Supporting this approach is a data from a study by Patel et al 2016 who reported that effective communication led to responsive and tailored care in women who received high-quality care from teams of health professionals²³.

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3 The American Heart Association emphasises the importance of measuring the self-reported
4 health status (i.e. symptom burden, functional status, and health-related quality of life) of
5 patients with cardiac disease as it is not only a necessary component of clinical risk scoring,
6 but consistent with a holistic view of health and the goals of patient centred care ⁵¹.
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14 **Conclusion**

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16 Our meta-synthesis revealed that there is a need for tailored, responsive care and gendered
17 models to guide shared decision-making and empathetic counselling across the
18 reproductive lifespan for women with cardiac disease. Our findings were consistent with the
19 experiences of women with other non-communicable diseases in pregnancy, such as chronic
20 kidney disease and diabetes ^{52 53} and similar to studies of non-pregnant women with cardiac
21 disease ^{54 55}. Our study identified opportunities to improve shared decision-making whereby
22 clinicians understand the social context (her family, employment and other responsibilities)
23 of women and their goals, values, and preferences for health. Shared decision-making can
24 facilitate effective communication between a woman and her clinician to develop a shared
25 understanding of the problem and generate a mutually acceptable evaluation and
26 management plan.
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Acknowledgments

The authors would like to thank Sabina Belli for editing this paper.

Sources of Funding

This study was unfunded.

Conflict of interest

None

Author contributions

The study was conceived by ES. AJD designed the study. YK undertook the literature search and screening with assistance from AJD. YK, AJD and ES critically appraised the papers. YK and AJD undertook the initial analysis with input from all authors (ES, KL, MP and WAP). AJD wrote the manuscript, all authors edited and approved the final manuscript.

Data sharing statement

All data used in this meta-synthesis is available in the public domain.

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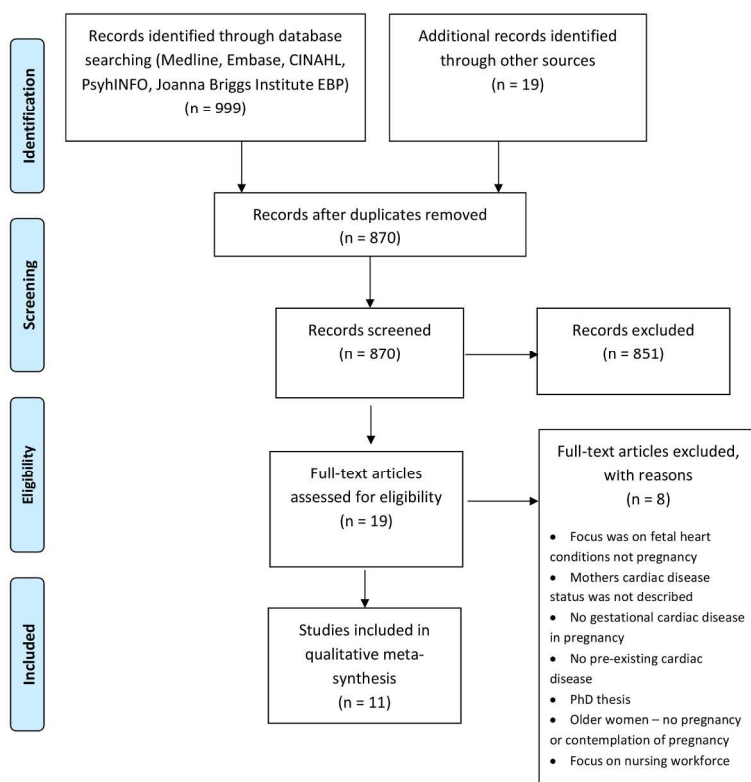


Figure1. PRISMA Flowchart of Cardiac Disease in Pregnancy

Figure1. PRISMA Flowchart of Cardiac Disease in Pregnancy

209x296mm (240 x 240 DPI)

Supplementary data-

Appendix 1: Full search strategy

Bibliographic Database	Search strategy
MEDLINE 1996 – 6 October 2016	<ol style="list-style-type: none"> 1 Cardiac disease.mp. or Heart Diseases 2 Postoperative Complications/ or Heart Transplantation/ or heart transplant.mp. or Heart Failure 3 Rheumatic heart disease.mp. or Rheumatic Heart Disease 4 Adult/ or Hypertension, Pulmonary/ or Heart Defects, Congenital/ or congenital heart disease.mp. or Cardiac Surgical Procedures/ 5 Hypertension/ or Cardiomyopathies/ or Cardiovascular Diseases/ or Arrhythmias, Cardiac/ or Heart Defects, Congenital/ or Heart Diseases/ or Cardiomyopathy, Hypertrophic/ or genetic cardiac disease.mp. 6 Arrhythmias, Cardiac/ or Myocardial Infarction/ or Atrial Fibrillation/ or chronic arrhythmia.mp. or Tachycardia, Supraventricular/ or Coronary Disease/ 7 1 or 2 or 3 or 4 or 5 or 6 8 Pregnancy Complications, Hematologic/ or Pregnancy, Unplanned/ or Pregnancy Maintenance/ or Pregnancy, High-Risk/ or Pregnancy, Unwanted/ or Pregnancy in Adolescence/ or Pregnancy, Multiple/ or Pregnancy Outcome/ or Pregnancy Complications/ or Pregnancy/ or Hypertension, Pregnancy-Induced/ or pregnancy.mp. or Pregnancy in Diabetics/ or Pregnancy, Abdominal/ or Pregnancy Complications, Cardiovascular/ 9 Pregnant women.mp. or Pregnant Women/ 10 Infant Mortality/ or Pregnancy/ or Maternal Health Services/ or Prenatal Care/ or Pregnancy Complications/ or antenatal care.mp. or Socioeconomic Factors/ 11 Perinatal care.mp. or Perinatal Care/ 12 birth.mp. or Parturition/ 13 postpartum.mp. or Postpartum Period 14 8 or 9 or 10 or 11 or 12 or 13 15 Decision making.mp. or Decision Making/ 16 Shared decision making.mp. 17 "Delivery of Health Care"/ or Decision Making/ or Physician-Patient Relations/ or Patient-Centered Care/ or patient centered care.mp. 18 15 or 16 or 17 19 midwives.mp. or Midwifery/ 20 General practitioner.mp. or General Practitioners/ 21 Primary physician.mp. 22 Obstetrics/ or obstetrician.mp. or Practice Patterns, Physicians'/

	<p>23 cardiologist.mp. 24 Family Practice/ or Allied Health Personnel/ or allied health professional.mp. 25 19 or 20 or 21 or 22 or 23 or 24 26 7 and 14 and 18 and 25</p>
<p>EMBASE: 1996 - 6 October 2016</p>	<p>1 cardiac disease.mp. 2 rheumatic heart disease.mp. or rheumatic heart disease/ 3 congenital heart disease.mp. orexp congenital heart disease/ 4 Arrhythmias.mp. or heart arrhythmia/ 5 1 and 2 and 3 and 4 6 pregnant women.mp. or pregnant woman/ 7 pregnancy Complications.mp. or pregnancy complication/ 8 infant Mortality.mp. or infant mortality/ 9 perinatal care.mp. or perinatal care/ 10 birth/ 11 postpartum pain/ or postpartum hemorrhage/ or postpartum.mp. 12 6 and 7 and 8 and 9 and 10 and 11 13 decision making.mp. or decision making/ 14 medical decision making/ or doctor patient relation/ or decision making/ or patient participation/ or informed consent/ or shared decision making.mp. or interpersonal communication/ 15 13 and 14 16 midwives.mp. or midwife/ 17 general practitioner.mp. or general practitioner/ 18 general practitioner/ or primary health care/ or general practice/ or primary physician.mp. 19 obstetrics/ or obstetrician/ or pregnancy/ or pregnancy complication/ 20 cardiologist/ or heart disease/ 21 family Practice.mp. or general practice/ 22 16 and 17 and 18 and 19 and 20 23 21 and 22 24 5 and 12 and 15 and 23 25 limit 24 to ("qualitative (maximizes sensitivity)" and English and article and last 20 years)</p>
<p>CINAHL (EBSCO) 1995 - 11 October 2016</p>	<p>S1" cardiac disease " S2 (MH "pregnancy") OR "pregnancy" S3 MH "decision making, patient") OR (MH "patient centered care") OR ""wom?n cent* care" OR "patient cent* care" OR "wom?n* experience" OR "shared decision making"" S4 S1 AND S2 AND S3</p>
<p>PsycINFO (EBSCO)</p>	<p>1. cardiac disease</p>

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1984 - 18 October 2016	<ol style="list-style-type: none">2. MH "Pregnancy") OR "pregnancy"3. (MH "Decision Making, Patient") OR (MH "Patient Centered Care") OR ""wom?n cent* care" OR "patient cent* care" OR "wom?n* experience" OR "shared decision making""4. 1 AND 2 AND 3
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Section/topic	#	Checklist item	Reported on page #
TITLE			
A qualitative meta-synthesis review of the experiences of women with cardiac disease who have been, are pregnant or considering pregnancy	1	Identify the report as a systematic review, meta-analysis, or both. – meta-synthesis	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	3-4
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	5-6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. – N/A	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. – Appendix 1.	32-34
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	8-9

Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	8-9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	9
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	9
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	9
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	27
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	9
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	10-12
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	13-14
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	16-17
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	16, 18-27

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Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	27
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	27-28
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	28

For peer review only