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ORIGINAL ARTICLE

# Case Studies of the Perceptions of Women with High Risk Congenital Heart Disease Successfully Completing a Pregnancy☆

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**Purpose** Women even with moderate to severe congenital heart disease (CHD) seek motherhood despite posing significant health risks to themselves and their infant. This study explored their motivations and perceptions and compared them to those of women with low risk CHD who conceived.

**Procedures** Twenty women over 18 years with CHD who had a successful pregnancy were recruited, half of whom were identified as having a high risk cardiac abnormality. They completed a questionnaire and a semi-structured interview following which a thematic analysis was employed. Their medical records and clinical status were also reviewed and their current cardiac status graded by their attending cardiologist.

**Findings** Women with high risk (moderate to severe) CHD (n = 10) appeared to have similar motivations for conceiving as women with low-risk (mild) CHD (n = 10). Their decision to conceive seemed based on their own and at times unrealistic perceptions of the consequences of their CHD.

**Conclusions** Women with mild or more severe CHD had similar motivations to conceive tending to downplay the seriousness of their CHD. Their drive for motherhood appeared to be stronger than the drive for self care. It behoves clinicians, both obstetricians and cardiologists caring for women with high risk CHD to be knowledgeable of the effects of the CHD on the pregnancy and the impact of the pregnancy on the cardiac status.

**Keywords** Congenital heart disease • Pregnancy • Motivations • Risks • Perceptions

## Introduction

Advances in medicine and surgery over the past few decades have allowed approximately 85% of infants with congenital heart disease (CHD) to reach adulthood [1] resulting in an increasing number of women with CHD who wish to conceive. Little attention has been paid to the motivations of women with CHD proceeding to pregnancy, though there have been studies reviewing the motivations of healthy women. These motivations vary and include the women's innate biological predisposition to have children encouraged by their personal goals [2] as well the expected norms of society, both religious and cultural [3], and the influence of their partners [4] and close family and friends [5].

Haemodynamic changes occur in normal pregnant women as their bodies adapt to increased demands required for foetal growth, the stresses of labour and the post partum period [6] (Fig. 1). These changes becoming increasingly

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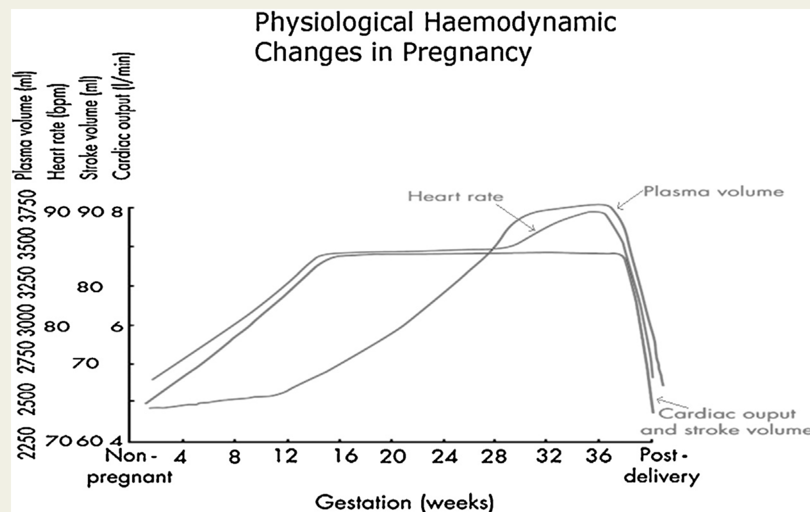


**Figure 1** Schematic diagram highlighting the physiological haemodynamic changes that occur during pregnancy (courtesy of Prof R Harper).

more significant in women with CHD who are faced with an additional mortality and morbidity [7]. Only 1% of pregnant women have heart disease. However it remains an important cause of maternal mortality and morbidity in western society [8]. It is associated with increased neonatal mortality and the early onset of labour [9]. In addition, mothers with CHD have an increased risk of at least four to six times the normal population, of giving birth to a child with a heart defect [8], with a higher transmission rate in genetically inherited heart disease [10]. Yet women with CHD continue to conceive despite the increased risks to both themselves and their unborn child. They seem to have a tendency to underplay and/or deny the severity of their medical condition, placing considerable reliance and therefore responsibility on their clinicians [7].

Most women born with heart abnormalities lead a life relatively unaffected by their CHD. Others may continue to have residual or secondary lesions even after surgical correction, leaving them chronically disabled, with a suboptimal quality of life [11] and a limited capacity to meet the demands of physical and social activities [12]. With such a burden on their health, their decision to conceive and complete a pregnancy is a complicated, unique and a constantly evolving process [13]. Their perception of the pregnancy risks seem to play an important role in their decision making and include such factors as the women's self-image, past history, healthcare and the concept of the unknown which includes the uncertainty of the future, conceiving and having a successful pregnancy [14].

The objectives of this study were to (A) understand the motivations of women with CHD to bear children, (B) test the correlation of the clinicians' and patients' assessment of risk of the CHD to the mother and child, and (C) assess if there are any discernable differences between the cohort with low risk CHD and those with high risk CHD.

# Methods

Twenty women over 18 years of age with CHD who had completed one or more successful pregnancies were recruited from a tertiary centre and private clinics. They were subsequently divided according to the severity of their CHD. One group consisted of women with clinically mild CHD (low risk group) as assessed by the cardiologist, and with an expected lower risk of complications arising from the pregnancy (n = 10). Another group consisted of women who were assessed as having moderate to severe heart disease (high risk group) with a potentially higher anticipated risk of complications arising from their pregnancy (n = 10). The attending cardiologists based their assessment on the women's current cardiac findings, their functional capacity and a review of their past history and records, and their cardiac interventions, if any, whether surgical and/or by catheterisation. The women themselves also rated the severity of their heart condition which was compared with that made by their cardiologist. Women were excluded from the study if they were deemed by their clinicians as emotionally or physically too unwell to be interviewed, were not fluent in English or were intellectually handicapped.

A written questionnaire recorded basic demographic information and included a list of the symptoms experienced. A semi-structured interview specifically constructed for this study and conducted by a single interviewer (K.N.), was recorded digitally and took approximately 30 minutes to complete. The interviews were carried out in person wherever possible and if not, via the telephone. The questionnaire focused on the women's motivations for having a pregnancy and the effect of their perception and understanding of their CHD and its associated implications with respect to the pregnancy. Supportive prompts were used

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