



# openheart Maternal mental health: a key area for future research among women with congenital heart disease

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## ABSTRACT

In this viewpoint, we respond to the recently published national priorities for research in congenital heart disease (CHD) among adults, established through the James Lind Alliance Priority Setting Partnership, with specific attention to priority 3 (mental health) and priority 5 (maternal health). Our recent policy impact project explored how maternal mental health is currently addressed in adult congenital heart disease (ACHD) services in the National Health Service, identified gaps and discussed possible ways forward. Our multidisciplinary discussion groups, which included women with lived experience of CHD and pregnancy, cardiology and obstetrics clinicians and medical anthropologists, found that while pregnancy and the postnatal period increase the mental health challenges faced by women with CHD, current services are not yet equipped to address them. Based on this work, we welcome the prioritisation of both mental health and maternal health in ACHD, and suggest that future research should focus on the overlaps between these two priority areas.

## INTRODUCTION

The recently published national priorities for research in congenital heart disease (CHD) among adults, established through the James Lind Alliance (JLA) Priority Setting Partnership, include both mental health and maternal health among the top 10 priorities<sup>1</sup>:

#3—What is the impact of living with CHD on mental health in adults and how can this be improved through access to psychological support and other therapies?

#5—What are the risks and limitations associated with pregnancy, childbirth, and motherhood for women with CHD, and what information and support is available?

Having recently completed a policy impact project focusing on the mental health of women with CHD during pregnancy and the postnatal period, we welcome the inclusion

of both areas as priorities, and suggest that future research focus on the considerable overlap between them. In particular, we argue that mental health should be considered a core component of the 'risks and limitations associated with pregnancy, childbirth and motherhood' in priority 5.<sup>1</sup>

Research attention to the experiences of pregnant women and new mothers with CHD is crucial. One per cent of all children have CHD,<sup>2</sup> with 13 born in the UK every day.<sup>3</sup> In recent decades, with advances in medical and surgical knowledge and technology, 97% of children with CHD have reached adulthood,<sup>4</sup> albeit with increased risk for cardiac morbidity.<sup>5</sup> However, even years after successful surgical repair and treatment, many adults with CHD face lifelong psychosocial difficulties, with high rates of depression and anxiety,<sup>6</sup> including anxieties about being 'normal'.<sup>7,8</sup>

The haemodynamic changes of pregnancy and the immediate postnatal period pose physiological challenges to women with CHD.<sup>9</sup> As such, pregnant women with CHD are classified as high risk, and often experience medicalised pregnancies and managed births.<sup>10</sup> For women with CHD, particularly those who live otherwise healthy lives, pregnancies may lead to emotional distress concerning one's identity and future, the immediate risk to cardiac function and the potential for life-threatening complications for both mother and baby.<sup>11</sup> Prolonged exposure to distress, in turn, may have cardiovascular consequences: a recent scientific statement from the American Heart Association suggested that, even within the general population, accumulated psychological stress places women at risk for cardiovascular morbidity in pregnancy, such that prepregnancy interventions should include a stress-reduction component.<sup>12</sup>

As seen in a previous investigation of the healthcare priorities of pregnant women with

heart disease, both congenital and acquired, the mental health impact of pregnancy is a key concern for women.<sup>13</sup> However, although women with heart disease prioritise mental health outcomes, the research literature emphasises the clinical outcomes of pregnancies complicated by heart disease, suggesting a gap between extant research approaches and women's experiences.<sup>13</sup> Moreover, while both the research literature and adult congenital heart disease (ACHD) clinical services tend to focus on the risks inherent in pregnancy, a successful pregnancy and transition to motherhood can be psychosocially normalising events which can boost the mental health of women with CHD.<sup>14</sup>

Between January and March 2022, we undertook a policy impact project which brought together researchers, clinicians and women with lived experience of CHD and pregnancy to inform service improvement in two National Health Service (NHS) Trusts (University Hospitals Birmingham and Birmingham Women's and Children's) and develop recommendations that could be applied more broadly. This project was the first to turn urgent attention to the mental health needs of women with CHD during pregnancy and the postnatal period. Group discussions with clinicians and women with lived experience identified (1) mental health needs and priorities specific to women with CHD; (2) barriers to accessing mental healthcare among women with CHD during and following pregnancy; and (3) recommendations for service improvement. We highlight two key findings from these discussions, showing that both clinical and research attention to the overlaps between mental and maternal health in ACHD are crucial.

### **Anxiety: a common experience for women with CHD in pregnancy and the postnatal period**

Anxiety was the mental health challenge mentioned most frequently in our multidisciplinary project discussions, by both clinicians and women with lived experience. Importantly, the discussions established that anxiety developed during pregnancy and the postnatal period may lead to further anxiety over time, with women feeling anxious about their future health, particularly in relation to parenting. Anxiety also extends to women's immediate families, especially their partners.

Our group identified anxiety as related to several factors, many of which arise from patient experiences of maternity care in both community and hospital settings.

### **Emphasis on risks (to both mother and baby) in ACHD discussions**

ACHD and obstetric teams emphasise risks to the baby's heart as well as risks to the mother's cardiovascular function. Women with lived experience identified this discourse of immediate and potentially life-altering risk as a key trigger of anxiety, which also places an emotional strain on the mother's partner and wider family. Additionally, both women with lived experience and clinicians said that, given the emphasis on risks within ACHD

maternity services, infrequent contact with obstetric care before 20 weeks of pregnancy can be anxiety inducing.

Our group also discussed the ACHD emphasis on risk beyond the context of pregnancy. ACHD teams tend to emphasise possible complications and limitations on what patients can do physically. This direct, honest and realistic communication style can be beneficial. However, without providing reassurance or a positive counter-focus on what the body can do, ACHD discussions can be anxiety-provoking, and some women live in fear of the future, even avoiding exercise for fear of straining their hearts.

### **Lack of CHD understanding across hospital departments**

When women with CHD encounter hospital departments beyond specialist ACHD services—such as the emergency department, delivery suite or postnatal ward—they may find that non-specialist clinicians minimise or dismiss their concerns.

### **Lack of CHD understanding in primary care**

Women with CHD may find it difficult to rely on antenatal and postnatal support in the community, because many midwives and health visitors are uninformed about CHD and sometimes give advice that conflicts with that of the ACHD team.

### **The social isolation of living with CHD**

The experience of growing up with CHD can be socially isolating, and this sense of isolation often persists into adulthood. Women with CHD may feel their experiences of pregnancy cannot be understood by friends, relatives, or other pregnant women (eg, National Childbirth Trust (NCT) group members). While support may be found through ACHD groups on social media, some of the experiences related by social media group members may be distressing.

In addition, a small number of women with CHD experience serious complications, requiring surgical or medical interventions in pregnancy. These experiences add a layer of trauma to an already anxious time, and can lead to a greater sense of social isolation, given how rare they are. While clinical teams are focused on delivering the best cardiac care, the deep psychological impact on the woman and her partner is left unaddressed, both in pregnancy and in the postnatal period.

### **Barriers to help-seeking: timing and availability of resources**

Both the clinicians and the women with lived experience emphasised that it is important to provide mental health support to women with CHD during pregnancy and the postnatal period. However, several barriers prevent patients with CHD from seeking and receiving appropriate support.

### **Specialist mental healthcare for the CHD population is difficult to obtain**

Women with lived experience and clinicians felt that psychological support would be most effective if delivered

by a therapist familiar with CHD-related issues. People with CHD have unique lifelong experiences that necessitate a psychologist or therapist with specialist knowledge. However, this is difficult to obtain without the help of the ACHD service, and patients must resort either to seeking treatment privately, facing long waits in the community, or forgoing mental healthcare entirely.

Mental health support is made available when women are unable to use it

Mental health support may be offered during the immediate postnatal period, but not later. This is often a time of great upheaval for women with CHD, who are overwhelmed by recovering from childbirth and caring for a newborn baby, and who may be burdened by frequent hospital visits related to their heart condition in the first few weeks following the birth.

### CONCLUSION AND IMPLICATIONS FOR FUTURE RESEARCH

While our policy impact project was designed to inform service improvement in two NHS Trusts, the outcomes of our multidisciplinary discussions suggest that the overlap between maternal and mental health in ACHD is an important area for future research. As the JLA Priority Setting Partnership has highlighted, adults with CHD face lifelong mental health challenges. Against this broader background, we suggest that, for women with CHD, these mental health challenges are particularly acute during pregnancy and the postnatal period, with current services not yet equipped to address them. With research on maternal mental health in ACHD still scarce, there is an urgent need for both cross-sectional and longitudinal studies that investigate the lived experiences of women with CHD in the preconception period, pregnancy, and the immediate and extended postnatal periods. Also needed is research on health service innovations to reduce barriers to accessing mental healthcare among pregnant women and new mothers with CHD, including trials focused on different modalities of prevention, intervention and joined-up care specific to this patient population.

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