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Pre-pregnancy counseling for women with heart disease: A prospective study

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ABSTRACT

Background: Women with cardiac disease and their infants are at a greater risk of mortality and morbidity during pregnancy. Expert groups recommend preconception counseling (PCC) for all women with cardiac disease so they are made aware of these risks. We have run a specialist maternal cardiac clinic since 1996. The aim of this study was to evaluate the experience of women who have received PCC within an established multidisciplinary tertiary clinic and to establish their views regarding the counseling they received.
Methods: Single centre prospective study using a patient questionnaire was given to women attending a specialist cardiac preconception counseling clinic from November 2015 to August 2016, with analysis of descriptive data and free text comments from the questionnaire responders.
Results: 40/65 returned patient questionnaires. Prior to the consultation fewer than half felt well informed regarding how their heart disease could impact upon pregnancy but a similar proportion felt nonetheless that they would be able to have a healthy pregnancy. Women reported two main areas of concerns, their own health (whether they would survive a pregnancy) and the health of their child. 15% of women reported that these concerns had prevented them from pursuing a pregnancy. Women reported high satisfaction rates with the clinic.
Conclusions: There is an increasing demand for PCC services for women with cardiac disease; our study is the first attempt to determine both the acceptability and the impact of PCC from the patient perspective. Patients reported a high level of satisfaction with the service provided.

1. Background

Women with cardiac disease (CD) face a greater than average risk of mortality and morbidity during pregnancy [1]. Their pregnancies are at greater risk of complications, including early delivery, emergency Caesarean section, postpartum haemorrhage [2–4] and cardiac complications, including thromboembolism, heart failure and particularly arrhythmia [5–7]. Moreover, the haemodynamic effects of pregnancy may accelerate disease progression [8–12]. Complications are not limited to the mothers, as the babies are more likely to be born preterm, and/or be small for gestational age [2]. They have at least double the risk of having a congenital heart lesion when compared with the background population. For some women this risk is even higher — for example with single gene disorders such as Marfan syndrome, with a recurrence rate of 50% [13]. Guidance from the European Society of Cardiology and from the Royal College of Obstetricians recommends that all women with pre-existing heart disease receive specialist pre-pregnancy counseling (PCC) prior to conception [14,15]. Women with heart disease appear to be amenable to counseling with the majority of women who are offered it taking the opportunity to attend [16].

PCC offers not only a discussion of the risks a woman will face should she wish to pursue pregnancy but is also an opportunity to review and adjust medication(s) and to update the investigation of her cardiac status. Few studies have examined how women with CD perceive their own health status and how this may impact upon pregnancy [17]. A previous Australian study of women with congenital heart disease (CHD) showed that although women were concerned about the health risks associated with their heart disease, they had a tendency to downplay the severity of their CD in relation to pregnancy — of ten women considered to have moderate/severe disease by their cardiologist, 8 thought their condition was only mild [17]. This reinforces the importance of detailed PCC. However, the most appropriate techniques for counseling have not been determined. The aim of this study was to evaluate the experience of women with CD who have received PCC within an established multidisciplinary tertiary clinic with a view to establishing the views of the women about the counseling they had received and how they thought it could be improved.

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2. Methods

A multi-disciplinary pre-pregnancy clinic for women with CD (predominantly CHD), was established in 1996 by cardiologists from the Royal Brompton Hospital and obstetricians from the Chelsea and Westminster Hospital. Whilst a CHD specialist should discuss pregnancy and contraception as soon as girls with any form of heart disease reach puberty, the multidisciplinary team is particularly concerned to make sure that they see women who have more complex heart disease (generally modified World Health Organisation II–IV) [18]. However, no restrictions are placed on women attending the clinic, and women are often referred by other cardiologists or maternity service professionals, as well as by general practitioners. During their consultation women are seen by an ACHD cardiologist specialising in pregnancy care, a specialist obstetrician, and more recently a nurse specialist (from 2015 onwards). On average a consultation lasts between 30 and 40 min. We encourage the women's partners or other family members to attend if appropriate.

During the clinical consultation patients are provided with individualised counseling about pregnancy, which as far as possible is evidence-based. Due to the absence of randomised trials in this area, much advice is based on experience and 'expert opinion'; analysis has demonstrated that the percentage and type of risk quoted correlates reasonably well with outcomes [19]. We discuss how CD may impact the fetus and address any particular issues with regard to genetic syndromes. For women who have an identified cardiac lesion related to a known gene, such as Marfan syndrome, we discuss options around in vitro fertilization and preimplantation genetic diagnosis, or additional invasive testing during the pregnancy to confirm a fetal karyotype. We discuss potential outcomes of pregnancy, including mode of delivery and the type of analgesia recommended for labour. We also address the short- and long-term impact of maternal cardiac function with regard to pregnancy. Drug regimens are reviewed for potential teratogenicity; the risks and benefits of discontinuing drugs prior to or following conception are outlined.

We provide women with advice about whether local or tertiary level antenatal care is preferable, and the optimum place of delivery. Contraceptive counseling (including leaflets explaining different types of contraceptive devices) and advice regarding preconception folic acid is given. Finally we also cover any more relevant general issues around PCC such as smoking cessation, optimization of maternal weight and reducing alcohol intake. Women and their partners are encouraged to ask questions and request clarification of any issues that they are unclear about. Following the consultation a comprehensive letter is sent to the referring doctor, the general practitioner and copied to the patient, documenting the advice given. Care is taken to use clear language that is as non-technical as possible.

Women's experiences of the clinic were captured by developing a questionnaire. As there was no published template, this had to be done by the authors (MC, LS and MJ). In 2001, the Institute of Medicine identified the different dimensions that constitute patient-centred care [20]. This framework was used to inform the content and structure of the questionnaire, which was further developed by expert consensus from the service providers. The questionnaire examined women's views assessing the following domains: 1) their involvement, 2) the extent to which they perceived that decision-making was shared, 3) the perceived quality/value of information that was provided, and 4) the appropriateness of the method of communication. A five point response scale was used to quantify opinions and the questionnaire was anonymised to encourage both participation and candour.

The questionnaire was piloted by 10 women (all included in final analysis). Invited free text responses were used to assess the adequacy of the included questions. All questionnaires were numbered prior to use. In addition, free text responses were invited with the lead question 'Do you have any other comments about your experience in the clinic?' Reponses were reviewed and no adjustments to the questionnaires were necessary.

Between November 2015 and August 2016, the questionnaire was given by MC or RP to all women who attended the PCC counseling clinic. They were asked to complete it at home once they had received a typed copy of their clinical consultation and were provided with a postage paid envelope to send back their responses. The questionnaire included a cover letter, which invited women to participate in the study and outlined its purpose, why the recipient had been chosen, the voluntary nature of participation and the anonymity of the response. Contact details of the professional team were clearly stated. Informed consent was indicated by the return of the completed questionnaire. The fixed question data was analysed descriptively. The free text data was analysed using thematic content analysis. All comments were read and key emergent themes were noted. Because no changes were needed after piloting, the original ten responses were included in the analysis presented.

2.1. Ethics statement

As this manuscript evaluates a clinical service it does not require formal NHS Research Ethics Committee review. Data analysis was performed by the direct healthcare team and subsequently anonymised.

The evaluation was considered to be ethically justified on the basis that there was no deviation from normal clinical practice. Participants were informed of the rationale for the study, the voluntary nature of the questionnaire and the anonymity of their response with informed consent being given by return of the questionnaire.

3. Results

Between September 2015 and August 2016, 65 women with heart disease attended for PCC and were given the questionnaire, and of these a total of 40 women completed and returned it (including the ten women in the pilot), a 62% response rate. The median age of women attending PCC was 32 years (range 21–40 years) and 33 women were nulliparous at review. Limited demographic data with corresponding mWHO scores of women who attended are listed in Table 1. Table 2 shows the demography and mWHO scores of those who did not complete the questionnaire. The underlying diagnosis was congenital heart disease in 38/40, with the remaining patients having a previous coronary artery dissection (1/40) and peripartum cardiomyopathy (1/40).

Table 1
Limited demographic data of women attending clinic.

mWHO score	Number of women (mean age)	Prior pregnancy (Y/N) (number of women)
4	4 (31)	Y (1) N (3)
3	8 (36)	Y (1) N (7)
2	20(30)	Y (2) N (18)
1	7(33)	Y (2) N (5)
Other	1 (37)	N (0) Y (1)

3.1. Questionnaire data

3.1.1. Women's' perceptions prior to counseling

Thirty five women (88%) reported that they had discussed pregnancy to some extent with a doctor in the past; 28 reported that this discussion had been with their cardiologist and 2 with their general practitioner. Five women failed to give us the relevant information. Women were then *asked to what extent they agreed or disagreed with the following statements*:

1. "Prior to the clinic appointment I felt well informed regarding how my heart condition may affect pregnancy"
   Of the 33 women who had never had a pregnancy, 9 (27%) either strongly disagreed or disagreed with this statement, 9 (27%) neither agreed nor disagreed and 15 (45%) either agreed or strongly agreed. Of 7 women who had previously had a pregnancy, 6 strongly agreed with the statement that they were well informed about how their condition might affect pregnancy and only one disagreed
2. "I feel confident that I will be able to have a healthy pregnancy"
   Of the 33 women who had not had a previous pregnancy, 9 (27%) either strongly disagreed or disagreed with this statement, 9 (27%) neither agreed or disagreed, 13 (39%) agreed and 2 (6%) strongly agreed. Those who had had a previous pregnancy tended to report a greater level of confidence with 6 of 7 women either strongly agreeing or agreeing with this statement.
3. "Prior to attending the clinic I was hoping for a future pregnancy"
   31/40 (78%) either strongly agreed or agreed with this statement, 4/40 (10%) neither agreed nor disagreed and 5/40 (13%) either strongly disagreed or disagreed.

Table 2
Limited demographic data of women who declined to attend.

mWHO score	Number of women (mean age)
4	3 (31)
3	3 (30)
2	7 (27)
1	31 (23)
Other	1 (30)

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