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Symptoms in women with Peripartum Cardiomyopathy: A mixed method study

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ABSTRACT

Objective: Peripartum Cardiomyopathy is a form of cardiac disease often associated with cardiac failure, occurring in late pregnancy or after childbirth. The anatomical and physiological changes in the mother associated with normal pregnancy are profound, and this may result in symptoms and signs that overlap with Peripartum Cardiomyopathy, leading to missed or delayed diagnosis. Women's experiences of Peripartum Cardiomyopathy symptoms remain poorly studied. The aim of this study was to explore and describe women's experiences of symptoms in Peripartum Cardiomyopathy.
Design: A triangulation of methods with individual interviews and data from medical records.
Setting: Mothers with Peripartum Cardiomyopathy diagnosis were recruited from Western Sweden as a part of research project.
Participants: 19 women were interviewed and medical records were reviewed by authors.
Data analysis: All interview transcripts were analysed using qualitative inductive content analysis to identify key themes.
Results: The main theme, meaning of onset and occurrence of symptoms is captured in the metaphor: *being caught in a spider web*, comprising subthemes, invasion of the body by experienced symptoms and feeling of helplessness. Symptoms related to Peripartum Cardiomyopathy started for 17 women during pregnancy and in two post partum and time from symptoms to diagnosis varied between three and 190 days (median 40). The physical symptoms were:shortness of breath, excessive fatigue and swelling, bloatedness, nausea, palpitation, coughing, chest tightness, bodily pain, headache, fever, tremor, dizziness, syncope, restless and tingly body and reduced urine output. Emotionalsymptoms were: fear, anxiety, feelings of panic, and thoughts of impending death.
Conclusions and implications for practice: Symptoms of Peripartum Cardiomyopathy were debilitating, exhausting and frightening for the women interviewed in this study. Health care professionals responsible for the antenatal care, especially midwives, need skills to identify initial symptoms of Peripartum Cardiomyopathy for early referral and treatment by a specialist. In order to give optimal care more research is needed to show how to improve midwives' knowledge of Peripartum Cardiomyopathy.

Introduction

Peripartum Cardiomyopathy (PPCM) is idiopathic disease, rare in high income countries and a diagnosis of exclusion. It is associated with, at times, severe heart failure (HF) occurring toward the end of pregnancy or in the months following birth. The left

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ventricle may not be dilated but the left ventricle ejection fraction is nearly always reduced below 45%. The Heart Failure Association of the European Society of Cardiology Working Group on PPCM defined it as*: An idiopathic cardiomyopathy presenting with HF secondary to left ventricle systolic dysfunction towards the end of pregnancy or in the months following delivery, where no other cause of HF is found. It is a diagnosis of exclusion. The left ventricle may not be dilated but the ejection fraction is nearly always reduced below 45% (Sliwa et al., 2010).*

The incidence and prognosis of PPCM varies globally (Elkayam, 2011). The true incidence is unknown, as the clinical presentation varies. Current estimates range between 1:299 (Haiti), 1:1000 (South Africa), and 1:2500- 4000 births (USA) (Sliwa et al., 2006, 2010; Blauwet and Cooper, 2011; Elkayam, 2011). No data exists on the prevalence of the disease in Europe (Haghikia et al., 2013). Assuming an incidence of 1:3500 to 1:1400 births would yield an expected incidence of up to 300 patients per year in Germany, with severe, critical cardiac failure in around 30 (Hilfiker-Kleiner et al., 2008). The incidence in Sweden has been estimated to be 1:9191 births (Barasa et al., 2012).

The anatomical and physiological changes in the mother associated with normal pregnancy are profound, and this may result in symptoms and signs that overlap with those usually associated with disease outside of pregnancy (Germain and Nelson-Piercy, 2011). The main/cardinal symptoms of PPCM are those of HF and include fatigue, shortness of breath, and fluid retention and thus diagnosis is often missed or delayed as initial symptoms are similar to those of hemodynamic changes in normal pregnancy or early postpartum period (Groesdonk et al., 2009; Sliwa et al., 2010; Germain and Nelson-Piercy, 2011; Givertz, 2013). An analysis of internet narratives of women with PPCM showed that symptoms overlap with normal discomforts of pregnancy, and thus create space for clinicians to overlook the seriousness of their situation (Morton, et al., 2014). A survey of women with PPCM participating in an online support group showed their frustration with the nursing staff (Hess et al., 2012) for being ignored, dismissed and neglected. Only 4% of the posts on the forum described interactions with health care professionals as positive.

The causes, risk factors, aetiology, treatment and prognosis of PPCM have been described elsewhere (Ferriere et al., 1990; Cenac and Djibo, 1998; Groesdonk et al., 2009; Sliwa et al., 2010; Elkayam, 2011; Germain and Nelson-Piercy, 2011; Bachelier-Walenta et al., 2013; Givertz, 2013). There are, however, a lot more questions that remain unanswered and women's experiences of symptoms of PPCM are rarely explored. As understanding specific conditions from the 'sufferers' perspective is a foundational starting point for caring (Watson, 2011), it is important to understand the subjective experience and meaning of PPCM from the affected person's perspective. The lack of research in this area points to the need for knowledge acquirement from those who are affected, to assist with differential and early diagnosis of PPCM. As part of a research project in Sweden on PPCM, the aim of this study was, through a triangulation of methods, to explore and describe women's experiences of symptoms of PPCM.

Methods

In order to address the research aim a triangulation of methods was used (Creswell, 2013) with data collected through semi-structured interviews and medical records, and analysed using qualitative content analysis and descriptive statistics. The study received ethical approval from the research ethics committee of Gothenburg (DNr.589-11).

Setting

In Sweden, women can access maternity services free of charge. Almost all births are in hospital; only approximately 0.1% are planned home births (Lindgren, 2008). Midwives in Sweden are first registered nurses educated in a first cycle three year university programme. After at least one year of working as a nurse, they undertake a 18-month programme at second cycle, leading to registration as a midwife. Midwives are autonomously responsible for care in pregnancy and childbirth in normal physiological conditions. In case of complications they refer women to a gynaecologist/obstetrician, however midwives are still involved in the care.

Participants

A purposive sample of 25 Swedish-speaking ambulatory patients was recruited via medical records from Western Sweden and asked for study participation by the first author (HP), who had no professional relationship with the participants. This sample comprised women with experiences of symptoms of PPCM (Elo et al., 2014). A total of 25, who met the inclusion criteria of having had a PPCM diagnosis according to the European Society of Cardiology (Sliwa et al., 2010) between 2005 and 2012, and able to speak Swedish, were contacted by telephone; three women declined participation due to lack of time and one due to difficulty with Swedish language, and two were excluded because they did not fulfil criteria for PPCM diagnosis. Nineteen women willing to participate were informed about study purpose and method and written consent for study participation was obtained.

Data collection

Data from the medical records of the 19 women were collected and the women were interviewed once, three months to seven years (median 43 months) after ending the index pregnancy. The interviews were performed by HP in a private room outside the clinic ($n=13$), or as telephone interviews when women lacked time for a face to face meeting ($n=6$). The interviewer strove to establish a trusting and confidential relationship by being calm and confirmative to the women's narratives in order to get in-depth descriptions of their experiences. First the participants were asked to complete a brief questionnaire of demographic characteristics, and thereafter an open question was posed: *'Will you describe your experiences of the symptoms of PPCM?'* Probing questions were posed such as: *'What do you mean? Can you elaborate further?'* to obtain a deeper understanding of the experiences. Interviews lasted between 20 and 90 minutes. Noteworthy observations of non-verbal cues were made during the interview process, e.g. crying, laughing. The interviews were emotionally touching; 15 of the participants were crying, two could laugh and two participants were neutral while telling about their experiences.

Data analysis

The interviews were recorded and transcribed verbatim. Transcripts were first compared with the audiotapes for accuracy; then, relevant information, such as emotional content and non-verbal behaviour, was noted from memos, field notes. All interview transcripts were then analysed to reveal themes in the interview data by content analysis, inspired by methods developed by Krippendorff (2013) and Elo and Kyngäs (2008). All phases during data analysis was done individually by HP, MB and MS and later discussed together for conformity of the interpretation of interview data and categories. Initially, texts from each interview were read through independently by HP, MB and MS to get an overall