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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. Emotional symptoms 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.

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### 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

sense of the data. In the second phase, the text was read again and parts related to the aim (such as, reported symptoms) were identified independently by HP, AB and MB. In the third phase, the text was reread and units of analysis describing meaning of symptoms were separated. Notes and headings were written in the margins to describe all aspects of the content related to the symptoms. In the fourth phase the units of analysis together with the notes and headings were documented in separate sheets to summarise the description of women's experiences of symptoms, by HP and MB. Data regarding symptoms, mode of delivery and time after diagnosis at the time of interview were retrieved from interviews and confirmed by medical record review. All excerpts used in this paper to illustrate women's experiences have been translated into English.

## Findings

Maternal characteristics, and delivery outcomes, are described in Table 1. The age of the women ranged between 28 and 46 years (median 38) at the time of interview. Marital status, education, and employment status are all given as recorded at the time of interview. In 17 women the symptoms started during pregnancy and in two, post partum. Gestational age at the time for onset of symptoms ranged from 14th to 38th week (median 32 weeks). The time between symptoms start to diagnosis of PPCM, was 3–190 days (median 40). Fourteen women had pregnancy-induced hypertension and 13 had pre-eclampsia. Birth occurred in gestational week 28 to 42 (median 37). Mode of childbirth was 13 by caesarean section (four elective and nine emergency), and six had vaginal birth. Four women had twin pregnancies. One child had cerebral palsy. None of the women had given birth to another child after the index pregnancy at the time for interview; (10 months to seven years after they received the PPCM diagnosis); two had adopted a child. Seven women had a desire to give birth again (one of them was interviewed at three months after a child birth), and two women had adopted a second child. Ten women never wanted to be pregnant again, specifically due to the risk of PPCM. Data presented in Table 1 have been extracted from participants' medical records and interviews.

### *Being caught in a spider web*

The meaning of onset and occurrence of symptoms is captured in the metaphor: *being caught in a spider web*, comprising the invasion of the body by experienced symptoms and feeling of helplessness.

### *Symptoms experienced*

The onset and occurrence of physical and emotional symptoms are illustrated in Fig. 1. All women reported more than one symptom.

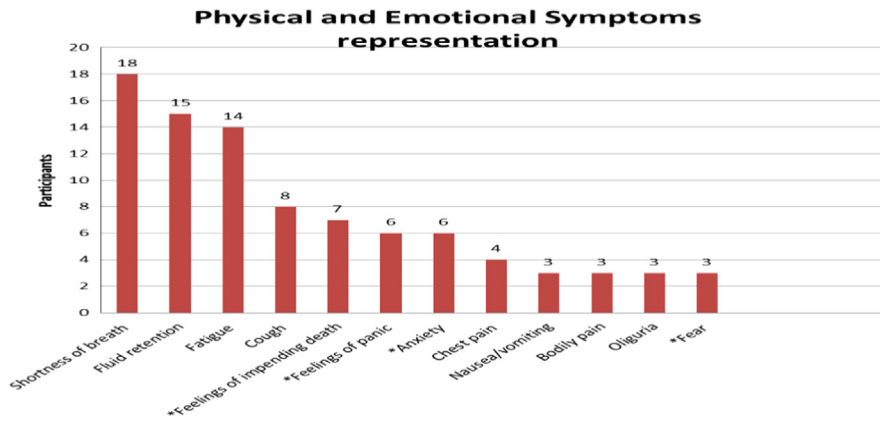
Among physical symptoms, *shortness of breath* was the most prevalent, reported by 18 of the 19 women (95%). Aggravated symptoms were described by one woman as 'putting a wine cork into the trachea' (P5). Fluid retention was present in 15 women (79%), 10 of whom had fluid retention in the legs which led to confined movements and was related to a feeling of 'feet like balloons' (P15), and 'hurting legs' (P17). Further fluid retention in the body was expressed as, 'labia like an orange' (P9) and 'a pit when pressing on the stomach' (P4, P11). Fourteen women (74%) reported *excessive fatigue*, described as 'impaired capacity' (P 13), 'low energy level' (P14), and 'last forces were used to keep going' (P13). *Palpitation* was described by one woman as, 'like a little person standing inside the chest banging on the sternum' (P18). *Cough* was experienced by eight women. Other symptoms

**Table 1**  
Characteristics of women with Peripartum cardiomyopathy.

<b>Age, years, mean (SD)</b>	37 (5.8)
<b>Range</b>	28–46 years
<b>Marital status, n (%)</b>	
<b>Married</b>	16 (84)
<b>Divorced</b>	1 (5)
<b>Living alone</b>	2 (10)
<b>Education, n (%)</b>	
<b>High school</b>	6 (32)
<b>Higher education &lt; 3year</b>	2 (10)
<b>University &gt; 3 year</b>	11 (58)
<b>Employment, n (%)</b>	
<b>Working</b>	15 (79)
<b>Maternal leave</b>	3 (16)
<b>Sick leave</b>	1 (5)
<b>Previous birth, n (%)</b>	
<b>Yes</b>	10 (53)
<b>No</b>	9 (47)
<b>Received treatment to conceive, n (%)</b>	
<b>Yes</b>	3 (16)
<b>No</b>	16 (84)
<b>Desire for more children, n (%)</b>	
<b>Yes</b>	9 (47)
<b>No</b>	10 (53)
<b>Perceived symptom presentation, gestational week</b>	Mean (SD) 28.5 (8) Range 14–38
<b>Received diagnosis, n (%)</b>	
<b>during pregnancy</b>	3 (16)
<b>Post partum</b>	15 (79)
<b>Missing</b>	1 (5)
<b>Time from symptoms to diagnosis of PPCM, days</b>	Range 3–190
<b>Mode of birth, n (%)</b>	
Vaginal birth	6 (32)
Caesarean birth	
Emergency	9 (47)
Elective	4 (21)
<b>Gestation at birth, week</b>	Range 28–42
<b>Twin births, n (%)</b>	4 (21)
<b>Neonatal care, n (%)</b>	13 (68)
<b>Presentation of PPCM, n (%)</b>	
<b>Acute</b>	12 (63)
<b>Gradual</b>	7 (37)
<b>Comorbidities, n (%)</b>	
<b>Gestational hypertension</b>	14 (74)
<b>Preeclampsia</b>	13 (68)
<b>Diabetes</b>	1 (5)

reported by fewer than five women were: *chest pain, nausea/vomiting, fever, headache, stomach ache, restlessness and tingling in the body, syncope/dizziness, bloatedness, palpitations, tremor* and signs like *oliguria*.

Emotional symptoms comprised some overlapping negative symptom: *feelings of impending death* ( $n=7$ ), *feelings of panic* ( $n=5$ ), feeling of *anxiety* ( $n=5$ ) and of *fear* ( $n=3$ ). Of the 19 women, eleven women reported at least one of the four emotional symptoms. Although these four feelings were not mutually exclusive, their clear separation in these findings was agreed by three authors.



**Fig. 1.** Symptoms representation by participants. \* Emotional symptoms. Of the 19 women, eleven reported at least one of the four emotional symptoms.

According to the women's descriptions in most women, symptom onset was acute ( $n=12$ ) and in the remainder it was gradual ( $n=7$ ). It was difficult for the women to express the experiences of symptoms in words for the midwives/health care providers, and sometimes diagnosis was delayed, as symptoms were dismissed as being signs of normal pregnancy, which is described in the following quotations: 'During labor, I stopped breathing...fortunately they called a cardiologist, who said it was heart failure, it was like I had all these months, he (cardiologist) said.' (P 16). 'It was after child birth I found out about heart failure, but doctor (cardiologist) told that it must have started during pregnancy'(P 4).

Women with longer duration of symptoms exhibited more expression of 'being caught' by the condition; e.g. there was more of suffering of physical and emotional symptoms including pain and misery. One woman with acute onset of symptoms described how she had to walk back to the ward (500 m) after a pathological echocardiography which she felt as incredible and tedious:

*Two days after child birth came breathlessness... I sought help at the hospital..., suspected a blood clot and I was sent home despite an abnormal electrocardiogram... I sought help again with wheezing... suspected iron deficiency because I had blood loss during delivery... and sent home again. My symptoms worsened and I collapsed at the pharmacy with 4 day-old baby in my arms. I went back to emergency room. ... I was totally exhausted and sat at the ward reception area after walking from the echocardiography unit. Then came a physician and informed about the heart (P11).*

Another woman with insidious onset of symptoms needed to seek emergency room help several times, but health care professionals failed to identify her symptoms, which were attributed to mental problems. According to her, HF developed during pregnancy but was diagnosed post partum:

*It all started at week 14-15... could not breathe... fatigued and coughing, could not lie down, walked around at the night, and fainted several times. It all got worse in week 20... I was on sick leave from week 25. ...After childbirth my shortness of breath was interpreted as constipation and I received laxatives and a blood transfusion due to anaemia. I started coughing blood foam... respiratory arrest and ended up on a ventilator. They discovered that something was wrong with my heart (P5).*

#### Feeling of helplessness

The narratives conveyed a feeling of helplessness which was obvious in relation to the developing of symptoms both during pregnancy, birth and post partum. A feeling of helplessness

developed successively as the overwhelming symptoms took over everyday life, and the condition was not given enough attention or priority, neither at regular visits to the antenatal midwife, nor at visits to general practitioners. The women experienced these health care practitioners as uncaring, and did not know where else to turn for help. Having symptoms such as feelings of drowning and water-logged feet and ankles, breathing difficulties and not getting help from health care professionals was dreadful. The expectation that pregnancy and childbirth will involve nothing but happiness fell apart with the distressing and persistent symptoms. A narrative from one of the women shows that she lived with a constant struggle between hope and helplessness during pregnancy. The ill-health led her to questioning: 'Is it worth it having a baby?' (P8). Another woman stated:

*I had bodily pain, it was painful to breathe and I couldn't talk... The pain was wandering from one shoulder to another and then throughout the body... felt helpless; I had no idea what to do (P17).*

Women with continued symptoms after birth found the situation very complex because of their own illness and inability to take care of a new-born baby. They were scared, angry and helpless. When the symptoms became unbearable, feelings of impending death emerged:

*After childbirth I was really big like elephant... I had trouble urinating. After an acute C-section, I had an enormous bleeding ... shortly after I got the chills and started vomiting and got re-operated to stop the bleeding, and had to stay in ICU for three more days and after that returned to the ward...I had continued problem with breathing. I was helpless and thought I won't be there for my baby's first birthday (P12).*

A woman that was interviewed five years after childbirth still had the experience very vivid in her mind in relation to what happened after the child was born and PPCM had not yet been diagnosed. Due to illness, an electrocardiogram and an x-ray had been carried out. Despite an abnormal electrocardiogram and an x-ray showing enlarged heart, the cause was interpreted as pneumonic, and she was sent home some days after birth. Continued malaise led her to seek emergency room care repeatedly for the same problems without getting adequate help. She also saw her general practitioner who missed the correct diagnosis, and allowed her to fly abroad. As the flight landed, she felt very ill, as if she was dying, but did not receive emergency care until authorities had received assurance of reimbursement from her home country. Since then, although it happened five years ago, the appearance of similar symptoms at times of stress reminds her of



how bad it was. 'Although I don't feel sick all the time, a constant reminder is there, making me anxious and sad...' (P19).

The feeling of helplessness also comprised powerlessness, and embedded in this powerlessness was fear, anger, future uncertainty and frustration. As an example, three of the women (P8, P12, P20) working in the health care field stated their feeling of powerlessness as a result of not receiving adequate response from midwives, despite their indication that something serious was going on; this attitude was perceived by them as uncaring.

## Discussion

To our knowledge, this qualitative study is the first, illuminating the spectrum of symptoms experienced by women diagnosed with PPCM. The narratives reveal that the onset and occurrence of symptoms was like an invasion; it was like being caught in a spider web with evolving symptoms and a feeling of helplessness.

Symptoms reflect how the patient feels and are a cry for help, reflecting not only the physiological aspects of the disease, but the associated impact on everyday life, mental well-being and expectations of the women. Symptoms relating to the development of PPCM, are prone to individual perception and are a subjective experience reflecting the disease itself (Ekman et al., 2005). Symptoms are mediated through a story that seeks to reach an understanding of the specific experience and its meaning to both listener and the narrator. Within a biomedical paradigm, clinicians regard a distinct malaise symptom as legitimate and meaningful only when it is linked to a disease. Specific symptoms are tied to specific diagnoses, in which measurement and power is built into various interpretations. If no objective pathology is linked to the symptom, it becomes 'homeless' (Scott, 2004) and the patient can be left out without help like being 'caught in a spider web'. European Society of Cardiology guidelines on the management of cardiovascular diseases during pregnancy emphasises that, the relief of symptoms by early identification and correct diagnosis is an important target to ease suffering (Regitz-Zagrosek et al., 2011).

Shortness of breath was the most commonly reported symptom of PPCM in our study (95%), followed by fluid retention either in legs or body (79%), and fatigue (74%). The frequent presence of these symptoms is in congruence with previous review studies of common symptoms during pregnancy, showing the prevalence of shortness of breath to be 70% (Germain and Nelson-Piercy, 2011). Studies from Taiwan, USA and Australia found fatigue in pregnancy 87% to 97% of women (Zib et al., 1999; Chou et al., 2003; Chien and Ko, 2004), peripheral fluid retention as 60% (Elkayam et al., 2005) to 80% (Germain and Nelson-Piercy, 2011), and also tachycardia in 62% of the women (Elkayam et al., 2005). Other symptoms described in our study have also been reported in earlier research in women with PPCM; such as cough, orthopnoea, paroxysmal nocturnal shortness of breath in a study from Italy (Moioli et al., 2010); dizziness, non-specific precordial pain (50%), abdominal discomfort, and palpitations in studies from the United States (US) (Weinblatt et al., 1995; Abboud et al., 2007). Symptoms that were found in our study but not reported in previous work are: fever, headache, restless and tingly body sensations, feeling bloated and emotional symptoms like feelings of panic, feelings of impending death, anxiety and fear. More studies are needed in order to verify the symptoms related to PPCM.

Fatigue was one of the most common symptoms, described by 74%, i.e. 14 out of the 19 women interviewed. The symptom fatigue is difficult to assess as pathologic, as there are physical, psychological, and situational factors predisposing a woman to fatigue during pregnancy. Despite this, it is important to recognise fatigue as a real problem with potential negative impact on pregnancy outcome (Bialobok and Monga, 2000). Pregnancy fatigue has been

linked as one of the predictors in a study from the Netherlands for persistent fatigue up to one year post partum (Bakker et al., 2014).

Other symptoms, such as maternal anxiety and life stress, have been related to an increased risk of depression during pregnancy in previous research (Lancaster et al., 2010). The women in our study, who experienced emotional symptoms including feelings of impending death, panic, fear and anxiety, may be more susceptible to develop depression as a result of their malaise not being explained adequately. More research is needed to explore unexplained symptoms and their long-term consequences.

Common renal symptoms in pregnancy include nocturnal urinary urgency and stress incontinence. Up to 95% of pregnant women complain of urinary frequency, the cause of which appears to be multifactorial including changes in bladder function, and not solely the effect of the gravid uterus (Germain and Nelson-Piercy, 2011). In our study respondents complained of the opposite, reduced urine output, but this was not recognised as a serious problem by midwives. This emphasises the importance of listening to the affected women.

The symptoms of PPCM reported by the women in our study are similar to common symptoms in 'normal' pregnancies which probably is the reason why the women felt so helpless. Many of the women did not receive timely help for their symptoms leading to feelings of being scared, angry and sad. Another expression of helplessness was defencelessness and this included losing control over their own body and daily life. In earlier research it has been described that the act of surviving a life-altering event can result in survivorship by altering continuity of identity (Peck, 2008). Women may experience an altered identity because of limitations related to symptoms in their everyday chores. The vulnerability to the feeling of losing control with fear and anxiety may be enhanced by the changed social relations as a result of lacking stamina and experience that life is unpredictable. The women in our study seemed to be vulnerable to psychological ill-health because of experienced deprivation of strength probably related to the lack of adequate help for their symptoms. For example some of the women mentioned that their symptoms were mistaken as psychological, whereas others had to struggle to make themselves understand that it was serious and something really was going wrong even though laboratory findings were normal. However, more research is needed to increase our understanding about how women with symptoms of PPCM are affected in their daily lives.

The constellation of symptoms, such as fear of death, anxiety, future uncertainty along with shortness of breath suggests that women with PPCM experience significant distress and powerlessness indicating a need for appropriate action and support in the early stage. Anxiety related to inadequate explanations of patients' symptoms has direct physiological consequences on the heart. Anxiety may reduce physical capability by inducing tachycardia or reducing cardiac output (Chapa et al., 2014). Psychological stress may even cause acute pulmonary oedema (Tavazzi et al., 1987). Results from our study where the midwives appeared to be uncaring, contradict the synthesis of three qualitative studies from Sweden focusing on midwifery care approach to childbearing women with increased risks (Berg, 2005). This study describes that, 'the midwife's weapon is genuine caring in caring for the genuine – that is, a dignity-protective, caring relationship based on embodied knowledge and a balance between the medical and natural perspectives' ((Berg, 2005) p. 19). The challenge is to support normal physiological pregnancy and childbirth, but simultaneously to identify deviations from the normal and act accordingly (Berg, 2005). Transferring this knowledge to our study, it is crucial not to neglect such symptoms that the women with developing PPCM reported, rather midwives need to attempt a high level of suspicion in women with persisting and aggravated symptoms. A woman-centred approach to the care of childbearing

and child birthing women is essential for optimal care, also for women at high risk (Berg et al., 2012) like women with symptoms of, and diagnosis of, PPCM.

#### Strength and limitations

A main strength of this study is its originality. It is to our knowledge the first study using triangulation of methods, including both qualitative and quantitative data to explore symptoms in PPCM. The use of women's narrative is an important scientific tool in order to understand the meaning of getting this illness. Although the sample consists of just 19 women, and is collected from a single setting, we believe that our data and the findings are important for deep understanding of women with PPCM. We found that many of the delineated stories were similar with respect to experienced symptoms (thus confirming data saturation), but threats to the validity of the narratives cannot be excluded. Credibility and validity was conducted in several ways (Elo et al., 2014), e.g. mixed method in data collection facilitated validation of data through cross verification from medical records and personal interviews. Peer debriefing was conducted, with all co-authors checking the final analysis. Selection bias may have occurred in the review of medical records as the criteria for diagnosis of PPCM have widened since 2010 (Sliwa et al., 2010). This can be a particular problem with retrospective cohort studies where exposure and diagnosis have already occurred at the time individuals are selected for study inclusion. However, the diagnosis is rare and cases are therefore well remembered by treating doctors and the method we used, to contact all cardiologists in the hospitals in the region and to go through all records from women with both a birth diagnosis and a diagnosis of heart failure should have ensured that all cases were found. Rumination bias was avoided by ensuring no connection, eschewing empathy, maintained rationality and independence between interviewer and the interviewed women. Interviewer bias was avoided by asking the questions to all participants in the same way, and putting the interviewees at ease by asking a general, easy-to-answer question first. Furthermore, interview locations were chosen by participants to ensure comfort and confidentiality for them. Interviewees' responses were captured accurately by probing unclear descriptions to eliminate response bias. There was a risk of recall bias for onset of symptoms described by the women, as the initial symptoms may be symptoms of physiological pregnancy. There is effectively no way of knowing whether the initial symptoms were those of a normal pregnancy or PPCM, especially if it is the mother's first pregnancy. However, regarding recall bias, previous studies found that long-term maternal recall is both reproducible and accurate in relation to pregnancy and birth (Yawn et al., 1998; Tomeo et al., 1999). We can argue this as the symptoms have been identified in earlier quantitative studies (Weinblatt et al., 1995; Zib et al., 1999; Chou et al., 2003; Chien and Ko, 2004; Abboud et al., 2007; Moioli et al., 2010; Germain and Nelson-Piercy, 2011). Although there exists some evidence about reproducibility in our study, it is possible that women could be attributing symptoms to PPCM post-diagnosis that were just normal pregnancy-related. These issues need to be addressed in further longitudinal research.

The study did only include Swedish speaking women. The reason for this limitation is that, (1) the interviewed women needed sufficient Swedish language to express themselves and thus yielding meaningful and rich stories to fulfil the purpose of the study and (2) lack of financial study resources for included women speaking other languages. This is a major study limitation and of course more studies need to be done in non-Swedish speaking women where the challenges are even greater because of language problems; to provide good care for women who have difficulties expressing their symptoms.

#### Conclusions and clinical implications

The findings from this small study broaden our understanding of the hardship and personal suffering that these women with PPCM experienced. A delayed diagnosis of PPCM may thus have great impact on women's daily life/health. Symptoms of PPCM experienced by the included women are debilitating, exhausting and frightening. Health care professionals, and especially midwives who mostly are the primary antenatal care givers, need to develop competence and clinical skills to be able to detect PPCM symptoms earlier and differentiate them from normal physiological changes in pregnancy, and midwives need to understand the value of early referral for suffering women to a doctor. This is the challenge for all midwives.

#### Conflict of interest

None.

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