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What do we know about Peripartum cardiomyopathy?

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Peripartum cardiomyopathy (PPCM)

- Heart failure during pregnancy or within 5 months after delivery
- Incidence and prognosis varies globally - 1:299 (Haiti), 1:1000 (South Africa), and 1:2500- 4000 births (USA), 1:5719 (Sweden), 1:20000 (Japan)
- Enlarged heartmuscle - Poor pumping capacity

*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. The left ventricle may not be dilated but the **ejection fraction** is nearly always **reduced** below 45%*



PPCM – some of the risk factors

- Obesity – HT, diabetes, cardiovascular disease
- Smoking, alcoholism, sedentary life style, heredity
- High blood pressure – preeclampsia, HELLP syndrome
- Personal history of heart disease including myocarditis (inflammation of the heart muscle)
- African - American descent
- Multiple pregnancies
- Women >35 years (Masoomi 2017)
- Imbalance angiogenesis – value of placenta growth factor (Mebazaa 2017)
- Association to diabetes (Dhesi 2017), increased uric acid (Sagy 2017), roll of cardiac biomarkers (Lau 2017)



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Delayed diagnosis

**Earlier detection can help avoid many
serious complications of peripartum
cardiomyopathy.**

(Fett JD., Future Cardiol 2013)



PPCM - Symptoms and signs

PPCM is often difficult to diagnose because the *symptoms* may overlap common *symptoms* in normal pregnancy.

(Germain et al, 2011; Sliwa 2010; Groesdonk 2009; Givertz 2013; Dekker 2016)



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Symptoms in women with Peripartum Cardiomyopathy: A mixed method study



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Table 1. Characteristics of women with Peripartum cardiomyopathy

Age, years, mean (SD) Range	37 (5.8) 28 – 46 years
Previous birth, n (%) Yes No	10 (53) 9 (47)
Received treatment to conceive, n (%) Yes No	3 (16) 16 (84)
Desire for more children, n (%) Yes No	9 (47) 10 (53)
Perceived symptom presentation, gestational week	Mean (SD) 28.5 (8) Range 14 - 38
Received diagnosis, n (%) ..during pregnancy ..Postpartum ..Missing	3 (16) 15 (79) 1 (5)
Time from symptoms to diagnosis of PPCM, days	Range 3 - 190
Gestation at birth, week	Range 24 - 42
Twin births, n (%)	4 (21)
Neonatal care, n (%)	13 (68)
Presentation of PPCM, n(%) Acute Gradual	12 (63) 7 (37)
Comorbidities, n (%) Gestational hypertension Preeclampsia Diabetes	14 (74) 13 (68) 1 (5)



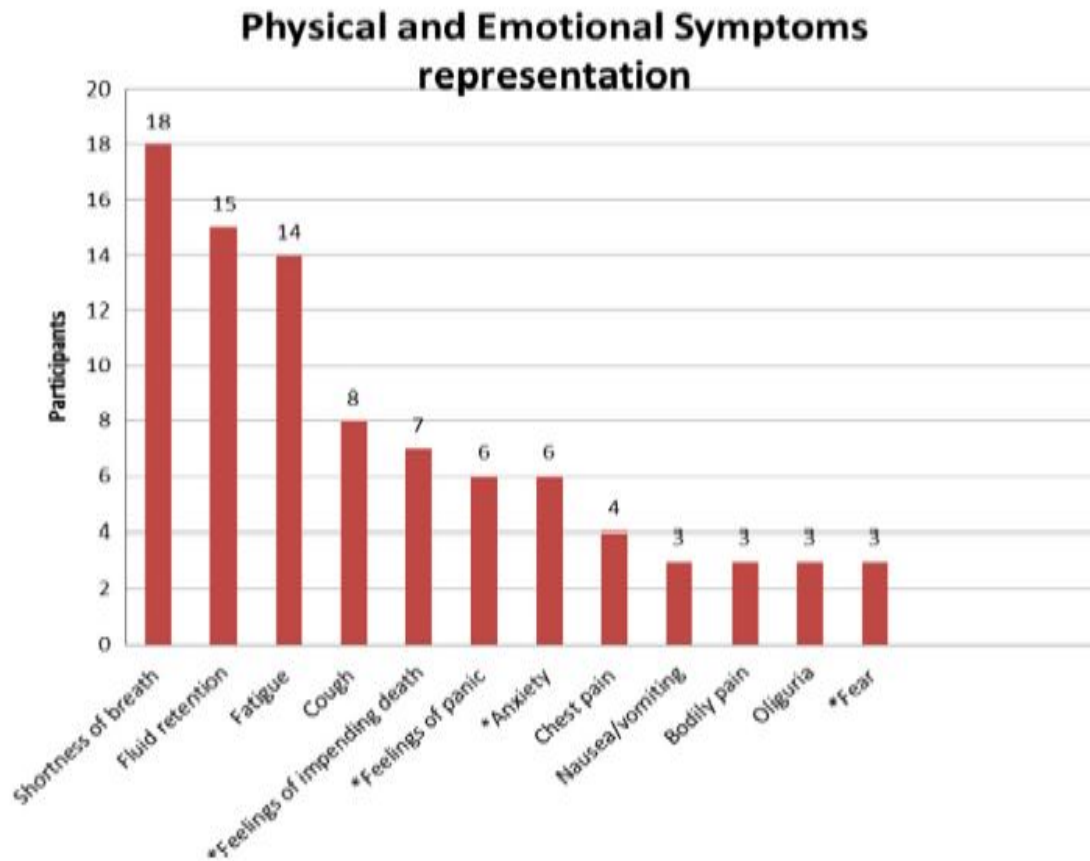


Fig. 1. Symptoms representation by participants. * Emotional symptoms. Of the 19 women, eleven reported at least one of the four emotional symptoms.



Results - the invasion of symptoms

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... 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).

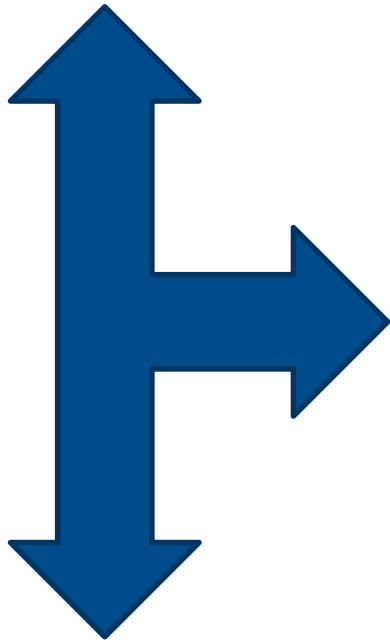


Results - feeling of helplessness

- *I had bodily pain, it was painful to breathe and I couldn't talk... felt helpless; I had no idea what to do (P17).*
- *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).*

Results

Invasion of the body by experienced symptoms



being caught in a spider web

Feeling of helplessness.



Care experience

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RESEARCH ARTICLE

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Experiences of health care in women with Peripartum Cardiomyopathy in Sweden: a qualitative interview study

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Abstract

Background: Peripartum cardiomyopathy is often associated with severe heart failure occurring towards the end of pregnancy or in the months following birth with debilitating, exhausting and frightening symptoms requiring person-centered care. The aim of this study was to explore women's experiences of health care while being diagnosed with peripartum cardiomyopathy.

Method: Qualitative interviews were conducted with 19 women with peripartum cardiomyopathy in Sweden,



Results - not being cared about - 1

No one believed me... I could not enjoy the pregnancy because I was in stress and worried all the time... difficult to make myself heard...(P1). //:"...things started getting crazy... my feet and ankles and calves became so swollen...Again I went to the midwife, but she told me it was "normal" (P4)



Results - not being cared about - 2

“...I was in the upper limit but I normally have low blood pressure, so the difference was greater for me but it was normal for her (midwife)... hypertension went unnoticed, which might have resulted in PPCM” (P15).



Results - not being cared about - 3

“A doctor who listened to my lungs, he said it was ok... I felt overly exhausted, but they (healthcare professionals) kept telling me that I had just been through childbirth and all this was normal... I know today that if they’d listened to me, I might not have been affected by this (PPCM)”.... “Later on, at the ICCU it’s the same feeling as earlier in the maternity ward. I asked her (nurse) for a diuretic so I can pee out because I was terrified that I would get pulmonary edema again. She (nurse) replied that it is not necessary. Well, I felt that it was crackling in the lungs but she insisted, but finally...I received a diuretic and peed 2 liters” (P18).



Results - not being cared about - 4

“... Deep down in my heart I knew I was dying, though they do not see me if I die now, difficult to get them to listen. I was looking at the door waiting for someone to come and see how bad I was” (P12).



Results - not being cared for - 1

“... I suspected nothing because no one said anything...one would think it is normal while carrying twins.

After the birth I gained even more water and looked like colossus... they said it is common... I could not walk in the corridor, when I was discharged. I said, excuse me, but should I breathe like this? I had to go home anyway.” (P6).



Results - not being cared for - 2

“I was at home less than 24 hours after discharge from the hospital after childbirth. I could not lie down so I sat up all night...I went to the emergency room with 4 days old babies. After ECG we had to go to another hospital (-), because they had no maternity ward here (-). No one knew what was wrong with me. After my arrival at gynecology-ward, I felt, I was not welcome there...I was left alone” (P17).



Results - not feeling secure

“...feeling a little bit hesitant to contact, and explaining myself all the time was hard ... she (midwife) did not respond adequately” (P18). //: “If they had taken a blood sample, they might have discovered that my heart was affected. I stopped peeing but I didn’t call the nurse-midwife because I had already called so many times and received an answer that there was no reason for worry. There was nothing else I could do but believe in midwives and just wait” (P12).



Results





Results: Positive experiences

- Adequate help quickly enough
- Were taken seriously
- Symptoms received label of PPCM.



Reflections

- A predominantly biomedical focus
- The rarity of the condition
- Individual competence
- organization (staff shortages, stress, etc.).
- Person centered care – based on narratives

Take home message

Clinical

- Symptoms of PPCM are debilitating, exhausting and frightening for the women.
- Need of skills to identify initial symptoms of PPCM for early referral.
- Impact of delayed diagnosis of PPCM.

Educational

- Knowledge of PPCM to provide optimal care.

Organisational

- ❖ The importance of a person-centered and holistic approach and effective team work to minimize care suffering in the woman with PPCM.



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Thanks for your attention

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