

# Peripartum Cardiomyopathy

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Harshida Patel, PhD,  
MSc, ANP, Senior lecturer  
Institution of Health Care &  
Science, Sahlgrenska  
Academy, University of  
Gothenburg



Harshida.patel@gu.se

Sahlgrenska akademin



# Acknowledgement

**Participating women** for sharing their experiences

## Co-authors:

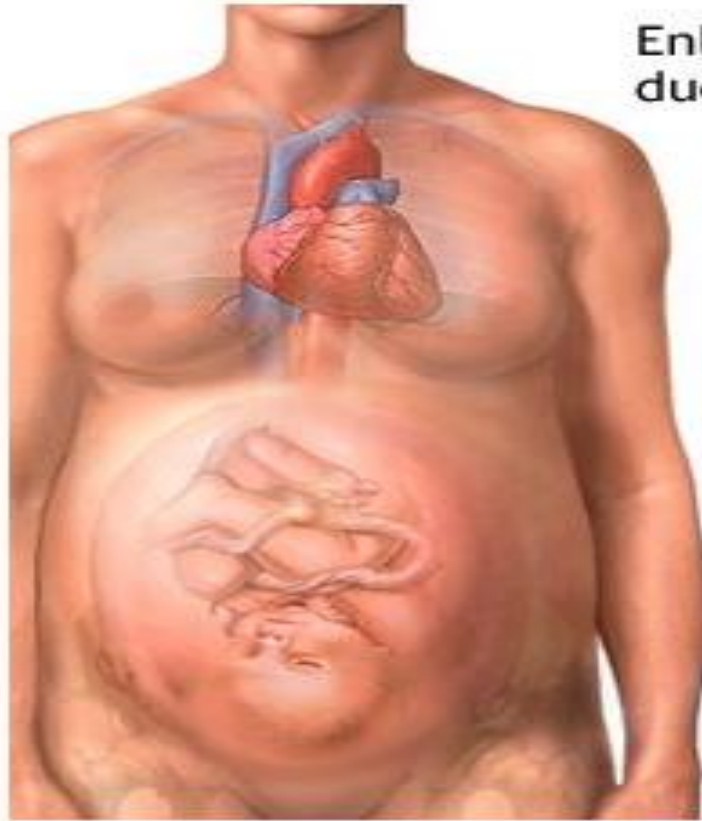
- Marie Berg, PhD, RN, RM, MPH, MNSc, Professor
- Maria Shaufelberger, Ass. Prof., PhD, MD
- Anders Barasa, PhD, MD, Agakhan hospital, Nairobi
- Cecily Begley, Professor, Trinity college, Dublin, Ireland

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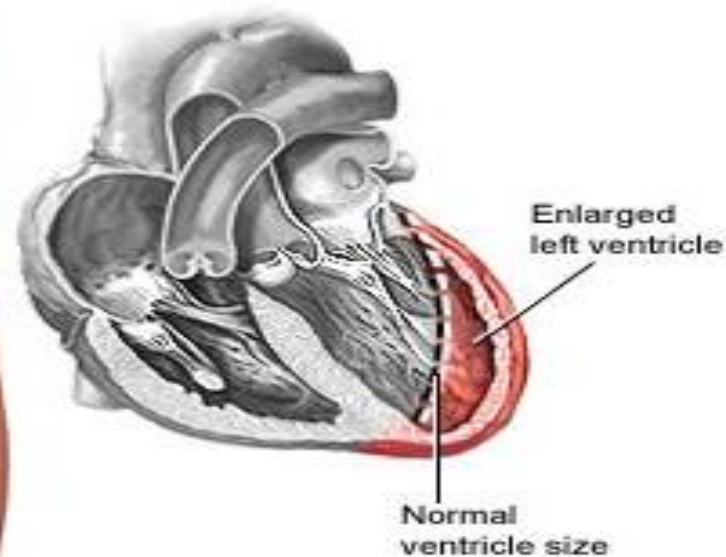
# Conflict of interest

None

# Peripartum Cardiomyopathy (PPCM)



Enlargement of left ventricle  
due to dilated cardiomyopathy



ADAM.

Peripartum cardiomyopathy is a rare disorder in which a weakened heart is diagnosed within the last month of pregnancy or within 5 months after delivery, without other identifiable causes for dysfunction of the heart. The heart muscle becomes enlarged and weakened and cannot pump blood efficiently. Decreased heart function affects the lungs, liver, and other body systems.

# Incidence och prevalence

1:299 (Haiti) child birth,  
1:1000 (South Africa),  
1:2500- 4000 (USA)  
1:9191 (Sweden)  
1:300 (Germany)

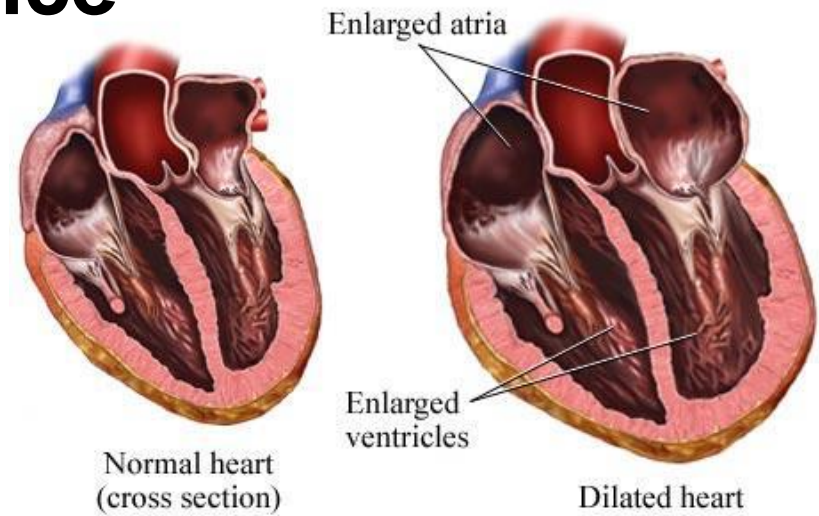
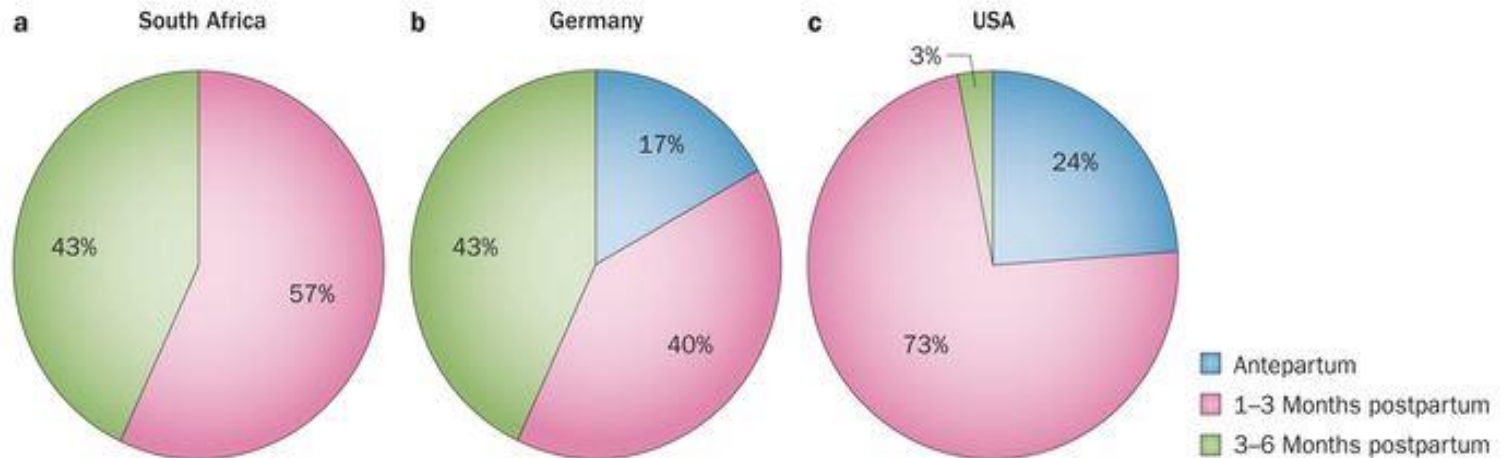


Figure 1: Time of onset of symptoms of peripartum cardiomyopathy according to country.



Hilfliker 2014

a | South Africa.<sup>9</sup> b | Germany.<sup>7</sup> c | USA.<sup>8</sup>

# What is already known?

- Overlapping symptoms
- Risk factors
- Prognosis
- Treatment
- Caring
- Setting



Photograph by Tatiana Gladskikh/iStockphoto

# Aim & Methods

- **Aim:** To describe and explore women's experiences of symptoms in PPCM.
- **Data collection:** Medical records & Interviews (n = 19 women)
- **Data analysis:** Content analysis



# Results

- Age 28 – 46 year (mean: 38)
- Parity: 10 women had given birth earlier and 9 were primiparas
- Pregnancy induced hypertension 9, Preeklampsia: 5
- 4 duplex
- Childbirth: pregnancy week 28-42 (median 37)
- Mode of delivery:
  - C - snitt: 4 planned, 9 emergency
  - Vaginal : 6
- No women had given birth after index child, 2 had adopted; 7 desired to give childbirth, 10 never wanted to be pregnant again due to the risk of PPCM.

# Symptom to diagnosis



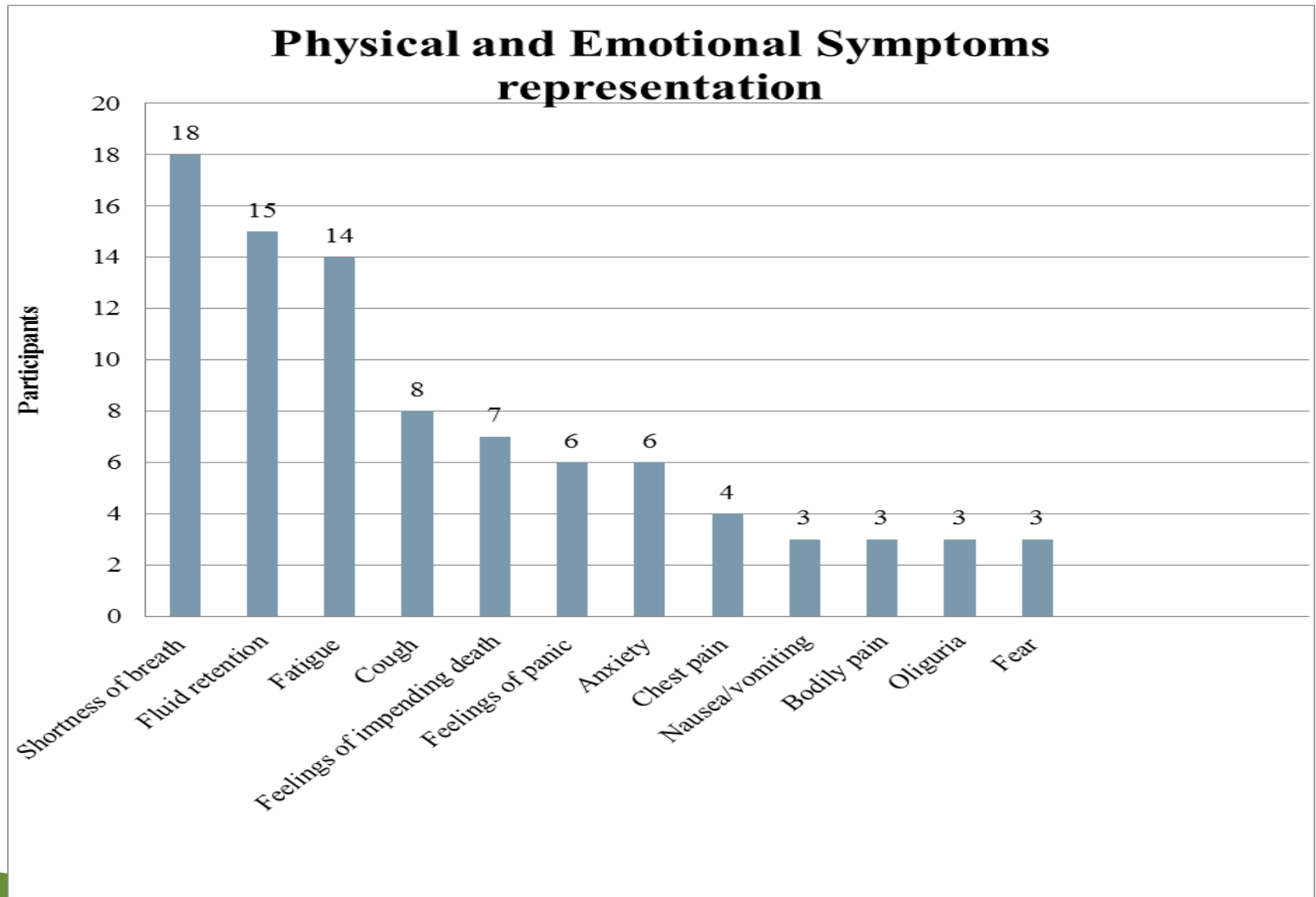
- Symptom start: pregnancy week 14-38 (median 32)
- Diagnosis:
  - During pregnancy: 3 women; pregnancy w. 24 - 37 (1 in w. 24 och 2 in w. 37))
  - Postpartum: 16 women; 1 – 35 days pp, (median: 6 days)
- Time from symptom start to diagnosis: 3–190 days (median 40)

# Being caught in a spider web



Tontenz.net

# Experienced symptoms



# Invasion of symptoms

*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)*

# 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... 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).*

# Feelings of hopelessness

- During pregnancy, childbirth and postpartum
- Uncertainty about where to turn for help
- Destroyed happiness of waiting children or becoming a mother
- Frustration at not being able to care for a newborn child
- Fear of the uncertain future
- feelings of impending death



# Where to turn to get help...

*“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)



# Feelings of impending death...

*“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).*

# Feeling of uncertain future...

*“Although I don’t feel sick all the time, a constant reminder is there, making me anxious and sad...”*

(P19)

# Clinical implications & future research

- Women centered approach
- Do not normalize pathological symptoms during pregnancy
- The training of midwives
- Rapid treatment when pathology is suspected
- Targeting midwives' knowledge of Peripartum Cardiomyopathy



# Highlights

1. Symptoms of PPCM overlap those of normal pregnancy, leading to delay in diagnosis.
2. Symptoms were debilitating, exhausting and frightening for the women; like being caught in a spider web comprising invasion of the body by symptoms and feelings of helplessness in women.
3. Health care personnel failed to identify symptom deviations in pregnancy, probably because of overlapping symptoms of pregnancy.