Title:

What Do We Know About Women With Peripartum Cardiomyopathy?

Harshida Patel, PhD, MSC

Inst. Health Care & Science, Inst. of Health Care & Science, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden Maria I. A. Schaufelberger, PhD Inst of medicine, Sahlgrenska academy, University of Gothenburg, Gothenburg, Sweden, Meidicine, Gothenburg, Sweden Cecily Begley, PhD School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland Marie Berg, PhD Inst of Health care and Science, University of Gothenburg, Gothenburg, Sweden

Session Title: Perspectives in Perinatal Health Slot: K 19: Tuesday, 31 October 2017: 9:00 AM-9:45 AM Scheduled Time: 9:00 AM

Keywords:

Peripartum cardiomyopathy, Pregnancy; heart disease and Symptoms

References:

- 1. Germain S, Nelson-Piercy C. (2011). Common symptoms during pregnancy. Obstet Gynecol Reprod Med. 21(11):323–6.
- Patel, H., Berg, M., Barasa, A., Begley, C., & Schaufelberger, M. (2016). Symptoms in women with Peripartum Cardiomyopathy: A mixed method study. *Midwifery*, 32:14-20. doi:10.1016/j.midw.2015.10.001
- 3. Patel, H., Schaufelberger, M., Begley, C., & Berg, M. (2016). Experiences of health care in women with Peripartum Cardiomyopathy in Sweden: a qualitative interview study. *BMC Pregnancy and Childbirth, 16*(1), 386. doi:10.1186/s12884-016-1178-3
- 4. Sliwa K, Hilfiker-Kleiner D, Petrie MC, Mebazaa A, Pieske B, Buchmann E, Regitz-Zagrosek V, Schaufelberger M, Tavazzi L, van Veldhuisen DJ, et al. (2010). Current state of knowledge on aetiology, diagnosis, management, and therapy of peripartum cardiomyopathy: a position statement from the Heart Failure Association of the European Society of Cardiology Working Group on peripartum cardiomyopathy. Eur J Heart Fail. 12(8):767–78.

Abstract Summary:

To fill the knowledge gap of peripartum cardiomyopathy in health care personnel. To prompt timely diagnosis and avoid unnecessary suffering it is important to listen seriously to, and respect, women's narratives and act on expressions of symptoms of peripartum cardiomyopathy, even those overlapping normal pregnancy symptoms.

Learning Activity:

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
---------------------	--------------------------

To fill the knowledge gap of symptoms of Peripartum Cardiomyopathy (PPCM)	Understand the overlapping symptoms of Peripartum Cardiomyopathy to those of the normal pregnancy
To broaden our understanding of the hardship and personal suffering in women experiencing PPCM.	The importance of the basic values and the need for a person-centered and holistic approach and effective team work to minimize care suffering in the woman with PPCM.
A delayed diagnosis of PPCM may have great impact on women's daily life and health.	

Abstract Text:

Peripartum Cardiomyopathy (PPCM) is a form of cardiac disease often associated with cardiac failure, occurring in late pregnancy or after childbirth (Sliwa et al., 2010). 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 PPCM, leading to missed or delayed diagnosis (Germain and Nelson-Piercy, 2011). The aim of the study was to describe women's experiences of symptoms of PPCM and received care, and identify the areas for improvement. Nineteen women were interviewed. The key themes were identified using content analysis. The main theme emerged is, The eternal suffering. The 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 (Patel et al., 2016). The care experiences are captured in *exacerbated suffering*, comprising subthemes, not being cared about, not being cared for and not feeling secure (Patel et al., 2016). Symptoms related to Peripartum Cardiomyopathy started for 17 women during pregnancy and in 2 postpartum, and time from symptoms to diagnosis varied between 3–190 days (median 40). Although women expressed miscellaneous experiences of care, majority of them described being not cared in adequate manner. The suffering was present in relation to the illness with failing health symptoms, but most of all in relation to not being taken seriously and adequately cared for by healthcare professionals. The deprecation of symptoms and missed diagnosis of PPCM can lead to a life threatening consequences. To prompt timely diagnosis and avoid unnecessary suffering it is important to listen seriously to, and respect, women's narratives and act on expressions of symptoms of peripartum cardiomyopathy, even those overlapping normal pregnancy symptoms. The analyses shows the importance of respecting women's narratives and positive interactions with midwives and obstetricians as well as the knowledge gap is highlighted in the maternity care personnel.

Key words: Peripartum cardiomyopathy; Pregnancy; Heart disease; Symptoms and Care; Qualitative methods; Childbirth; Women's experiences.