



Struggling with pain and disability: a qualitative study of the experiences of pregnant women living with pelvic girdle pain

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KEYWORDS

Introduction

Pelvic girdle pain (PGP) during pregnancy is a common complaint for women all over the world affecting 50% of pregnant population¹. This musculoskeletal pain is located within the pelvic area between the posterior iliac crest and the gluteal folds, with or without leg pain. The condition is complex and underlying mechanisms remain unclear. However, previous low back pain and/or previous PGP, previous trauma to the pelvis and previous deliveries are known risk factors^{2,3}. PGP has been frequently dismissed as trivial and inevitable although it significantly affects quality of life and causes considerable disabilities in daily activities such as walking, lifting, climbing stairs, lying flat on the back, turning in bed, housekeeping, exercising, and working, during leisure, hobbies and sexual life^{4,5}. PGP increases with advancing pregnancy and in one of three women the pain gets severe⁶. Fear of development of this pain can be reason to avoid a new pregnancy and some women have stated that PGP was the beginning of a chronic condition⁷. The syndrome also has a considerable social impact because of the high cost for society since it is one of most common causes to quit jobs among pregnant women⁸. Pregnant women with PGP are usually unprepared for these changes, which cause discomfort and hamper their day to day activities. They very often rely on nurses/midwives for accurate information and guidance. Hence their concerns have to be addressed adequately and measures to relieve these symptoms have to be incorporated while providing comprehensive nursing care, thus enabling pregnant women to lead a fuller life.

Materials and Methods

Research design- A qualitative phenomenological study was conducted in order to describe pregnant women's experiences of daily life with PGP. The qualitative method is used when there is limited knowledge of the phenomenon studied and can be particularly useful in describing a phenomenon from the women's point of view

Sample Characteristics- all participating women had well-defined PGP. They also encompassed a diverse range of characteristics including age, parity, socioeconomic status, type of family, religion, employment, and educational level.

Method of Data collection- Interviews were conducted at the antenatal clinic, or in the woman's home, depending on her preference. The interviewer created an open climate to enable the women to find the right words to express their lived experiences and to relate their experience of PGP during pregnancy.

Data Analysis- In this study a qualitative content analysis was used. At first, transcripts were read through repeatedly to obtain a composite perspective. Sentences or phrases containing information relevant to the questions were then selected. Finally, a systematic analysis of interview responses was per-

formed. Each interview was read through several times and codes relevant to the study's purpose were identified. The multiple codes were sorted into subcategories. These were then merged into main categories.

Results

Five main categories emerged; Pelvic girdle pain affects the ability to cope with everyday life; Coping with motherhood; Relationships between partners often strained; Questioning one's identity as defined by profession and work and; Lessons learned from living with PGP. The categories illustrated how the women's everyday lives changed. Not being able to meet their own or others' expectations placed a strain on their existence. It made them question and doubt their roles and identities as mothers, partners and professionals. They expressed that, as there was no effective treatment for PGP they did not look forward to further pregnancies. Knowledge gained was that women with PGP should seek help immediately, listen to their bodies, and acknowledge their limitations. Illustrative quotations are presented below and labeled by a synonym.

1. PGP affects the ability to cope with everyday life

a. Affecting Self-Care

Women expressed inability to carry out self-care activities. As the ability to stand sit, walking is affected due to PGP Women expressed how helpless they felt when carrying out self-care activities.

"I am unable to stand for few minutes even for brushing my teeth" (Thahira). Those with Family support expressed relief, where as those who did not expressed distress over their condition.

b. Inability to have a social life

Women said that they had lost control of their everyday lives.

"It was as if your whole life came to a halt, you had to struggle to achieve something" (Sandya).

Women expressed how they sadly missed the ability to socialize and meet people as they could before suffering from PGP. Some women said they could accept a duller daily life, since that was all they could manage anyhow. However, the knowledge that many of their friends were in the same situation made PGP easier to cope with. This support helped ease the pressure of maintaining a social life.

"This can feel very isolating. You feel different. You blame yourself for not being able to cope.... Some days you are able to force yourself to get up and get going, other days you just can't" (Cristina).

c. Dealing with people's reactions

The women felt stressed because they not only had to cope with constant pain, they also had to deal with other people's conceptions of a normal pregnancy. Women expressed frustration as they didn't fit in 'the normal pregnancy types'. Most of the women expressed being taunted by their in-laws and labelled them unfit for motherhood.

"Everyone says this pain is normal and I exaggerate it and I should learn to ignore it" (Amina)

2. Coping with motherhood

Inability to perform the mother role

The women expressed less ability to cope and take care of their older children. Just to go outside, dress the child, carry it, and get the child to bed at night was a problem, especially if the child was ill. Some women said that due to their pain, they were unable to appreciate their children. Their children craved hugging and closeness but they were unable to fulfill their children's needs because of their pain. The women had neither the strength nor the ability to play with them; they just wanted to be left alone. The women told how this made them feel sad, inadequate, and guilty.

"I feel so guilty when I look at my children. Can't cook what they like or even play with them. I feel so awful feeling like this" (Rehmath)

3. PGP puts a strain on the relationship

a. Role change is frustrating

Women felt frustrated because everyday chores were neither carried out to their liking nor when they wanted them to be carried out. However, they struggled to accept it.

Women said that PGP made them frustrated, more sensitive and irritable. They felt their patience was affected and they could easily explode. The women would say things they didn't mean, but knew it would lead to misunderstandings. They felt they really had to stress how they felt. Women expressed that their husbands didn't share the household chores and were insensitive to their sufferings in spite of the struggle they were undergoing. They long for some help and understanding from their spouses.

"It must feel strange to him that I can't do certain things. I'm not sure he wants to know about it. He has a hard time realizing I don't really mean it. I said you just have to think a bit like me. Many things spring to mind that I really don't mean. To be in constant pain is hard. You are not yourself all the time" (Susan).

Some women were worried that these feelings could cause the relationship to break down. Others said that PGP had brought them closer together. They said they appreciated partners who understood that their woman could not do everything as before. Without having to ask, their husbands were there for them.

"He copes and that's great. Of course I have to do my part. I can't depend too much on him. I have to realize we have to make the best of it. My husband has been great" (Lilly).

b. Sex life is greatly affected

Women said that it was difficult to maintain a normal sex life. The Pain kept couples apart. Other times sex was technically impossible.

"I dare not indulge in love making. The mere thought of the pain makes me repel. I know my husband feels bad, but I can't help it" (Simran)

4. Questioning one's identity as defined by profession and work

a. Loss of job

Many women resigned from their jobs as they couldn't cope with pain and their employer did not grant them sick leave.

Many regretted to have had a pregnancy with pain where they had to let go their jobs.

"I would have severe pain and was irregular to the office. After a month my employer told me to quit." (Ashwitha)

b. Decreased work

Women expressed difficulty accepting their decreased work capacity and/or their need for sick leave. They said they really wanted to work because it was an important part of their life. It was hard "just to be at home" without being able to do anything. The women felt edgy and bored at the same time. Some felt even a bit "loopy" and at worst, depressed. The women stressed how much they appreciated working part time. They were then part of working life and still able to maintain some sort of social life.

"I am struggling to cope with the demands of my job. It aches when I sit or stand. I don't actively involve myself in my work." (Sophie).

5. Lessons from living with PGP

a. advices to other pregnant woman and their partners

The women emphasized how it was of utmost importance that other pregnant women understood that PGP is painful and tiring. They need to take care of themselves and rest. That pregnancy, combined with PGP is hard work and puts a strain on your existence. But there is an end to the misery. The women related that it was important to seek help immediately, listen to their bodies and acknowledge their own limitations. Otherwise PGP would only get worse.

"To listen to one's body is easy advice to give, but hard to live up to. You have to embrace the idea that you have to rest to be rid of the pain... you just have to take care of yourself because it's an exhausting period of your life. It's tough being pregnant. Your moods go up and down." (Lilly).

The women pointed out that it was important to accept that they needed help and that they should not be too hard on themselves. They also expressed a general lack of consideration towards one another.

b. Not looking forward to another pregnancy

Women said that if they didn't experience PGP at the next pregnancy it would be like winning the lottery. They said they would love to have more children but were not looking forward to another pregnancy; not without effective treatment for PGP available.

"In the past we discussed three or four children. But now I will definitely not commit myself to another pregnancy until I am assured of a pain free pregnancy" (Rehmath).

c. Support from health care Professionals- Women expressed lack of understanding of their condition by their obstetricians. Midwives too seemed apathetic towards their sufferings.

Discussion

This study showed that PGP affected women's everyday lives, coping with motherhood, relationships with partners and the women's professional work. These results point to the complexity of living with PGP and how it influences all aspects of daily and social life. Health care professionals encountering women with PGP during pregnancy need to be aware of the women's complex life situation and provide adequate support. High levels of support are important for maternal well-being during pregnancy. Inadequate social support constitutes an important risk factor for depressive symptoms and reduced quality of life, and may lead to adverse pregnancy outcomes, as confirmed by earlier research⁹. It has been reported that second-time mothers grieve the loss of the exclusive relationship with their first child in the postpartum period, and report feelings of ambivalence, sadness, and guilt related to the rela-

tionship with the first child¹⁰. The women's relationships with their partners came to a head due to PGP. They became more dependent on their partners and the support they required was experienced as quite substantial. They were sad because their sex lives didn't work. PGP affecting women's sex life has been reported earlier but the women lacked knowledge of this². It is desirable for midwives to be supportive and provide couples with specific information about PGP. Couples in need of such information should be offered supportive sexual counseling on either a one-to-one basis or as couples during pregnancy. Adequate support may protect the couple from further strains on the relationship during the neonatal and early childhood period.

There seems to be a lack of knowledge and awareness of PGP, and how to support pregnant women with PGP in general and among caregivers and employers in particular. For example, overworked pregnant women are told by their caregivers to care for their bodies but fail to gain any real support. This creates anxiety as highlighted by HauklandFredriksen et al. who have problematized this contradictory discourse surrounding pregnant women, and particularly those with PGP¹¹.

Many women in this study stated they did not look forward to further pregnancies because of the pain and disability due to PGP. This finding has been reported earlier². It is also known that even if the risk for PGP increases in a future pregnancy, the risk is not absolute and most women with well-defined PGP will recover rapidly after pregnancy². Thus it is important that pregnant women with PGP receive support and relevant information to prevent anxiety and worry.

Conclusion

PGP severely affects pregnant women's everyday lives. There seems to be a lack of knowledge and awareness of PGP and how to support pregnant women with PGP both in society at large and among caregivers and employers. An awareness of how women with PGP attempt to manage and adjust to their everyday lives, motherhood, partnership and professional work can help caregivers provide these women with appropriate support to minimize difficulties during this important and rare phase in women's lives. Midwives have a crucial role in understanding the women's concerns and addressing them appropriately.

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