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'The sofa is my base in daily life': The experience of long-term, pelvic girdle pain after giving birth

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ABSTRACT

In this study, we investigated how women struggling with long-term pelvic girdle pain after giving birth experienced and coped in their daily life. We conducted individual interviews with 9 women with pain between 3 and 26 years after giving birth. We found that pelvic girdle pain results in significant challenges, influencing women's relationships with their children, partners and wider network. The pain demands careful planning and time for rest, influences women's ability to work, and creates feelings of isolation and shame. The informants connect the lack of formal diagnostic criteria for the condition to the low level of societal recognition.

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Pelvic distortion due to pregnancy is part of a normal physiologic and hormonal process in which joints and ligaments become pliable so pelvic elasticity can increase to enable the baby's passage through the birth canal. Distortion in pregnancy does not normally result in pain or trouble with walking; however, for some, pelvic and lower back pain limits activities like walking, standing or sitting down (Vleeming, Albert, Östgaard, Stuesson, & Stuge, 2008). In most cases, pelvic elasticity disappears shortly after giving birth, but for some women the pain and disability lasts (Airaksinen et al., 2006). Long-lasting pelvic girdle pain impacts everyday activities and quality of life (Stuge, Veierød, Laerum, & Vøllestad, 2004), and pain for more than three to six months is termed a long-term or chronic condition (Treede et al., 2015). The experiences of women with long-lasting pelvic girdle pain after giving birth have only been explored to a limited extent (Bjelland, Stuge, Engdahl, & Eberhard-Gran, 2013); our aim in this study, therefore, is to increase knowledge about this important topic. Although this study was conducted in Norway and reported rates of long-lasting pelvic girdle pain following birth are high in

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Scandinavian countries, the phenomenon is a universal problem spread across all continents (Kanakaris, Roberts, & Giannoudis, 2011).

Background

According to European guidelines pelvic girdle pain involves musculoskeletal pain localized from the level of the posterior iliac crest and the gluteal fold over the anterior and posterior elements of the bony pelvis (Vleeming et al., 2008). There is inconsistency and lack of consensus regarding clinical manifestations, terminology, definitions and treatment of pelvic girdle pain (Kanakaris et al., 2011). Moreover, the prevalence of the condition is uncertain, which is related to the fact that long-term pelvic girdle pain after giving birth is not acknowledged as a diagnosis in the ICD-10 system (Alappattu & Bishop, 2011). A precise diagnosis represents a basis for attention and relevant treatment in modern societies. A diagnosis, however, does not emerge by itself. Diagnose are definitions that are defined and redefined in “conversations” in society involving, for example, patients, medical doctors, media, and social security systems (Rosenberg, 2002). Johannisson (2007) terms a disease without a name or acknowledgement as “homeless,” highlighting how a diagnosis serves as an acknowledgement of the existence of a condition, challenge or problem. Just as a diagnosis can explain a condition and provide relief from feelings of responsibility, it can also affect a person’s life-world. Because of the disputed diagnosis and uncertainty regarding prevalence, it is difficult to find the exact number of women who receive disability benefits in Norway due to long-term and severe pelvic girdle pain after giving birth; in a report on maternity care, however, the authors claim that there are approximately 30 new cases in Norway each year (Norwegian Directorate of Health, 2005).

Because long-term pelvic girdle pain after giving birth is not accepted as a diagnosis, there is a concern that women with such challenges do not get the necessary help and support from the healthcare system. The lack of objective indicators leads to a situation in which the condition is approached as a subjective experience (Bjelland et al., 2013). In a prospective Danish study, Albert, Godskesen, and Westergaard (2001) found that among 206 women with pelvic girdle pain after delivery, 8.5% still had pain two years after giving birth. In a mini-review, Kanakaris et al. (2011) found that among women with pregnancy-related pelvic girdle pain, 1–2% report persistence of pain one year after giving birth. Researchers point to risk factors that worsen the prognosis for women with long-term pelvic girdle pain, including intensity of symptoms, prolonged duration of labor, age above 29 years, and certain demographic, psychosocial and socioeconomic characteristics (Kanakaris et al., 2011).

Improved knowledge is key to better understanding the situation of the women as well as that of their network and health professionals, and it opens additional pathways towards help and support. Although there has been growing interest among researchers regarding pelvic girdle pain after giving birth, the empirical evidence on this topic is still limited (Bjelland et al., 2013). For example, Stuge et al. (2004) found that stabilizing exercises and physiotherapy improve pelvic girdle pain and disability two years after giving birth; overall, however, evidence on the effect of exercise and physiotherapy is disputed (Almoussa, Lamprianidou, & Kitsoulis, 2018). Further, research focused on life with long-term pelvic girdle pain—for example exploring women’s experiences of living with this condition and how they cope in their daily life—is scarce.

While there have been qualitative studies on pelvic girdle pain most researchers have focused solely on women’s situation during pregnancy (Elden, Lundgren, & Robertson, 2013; Fredriksen, Harris, Moland, & Sundby, 2014; Fredriksen, Moland, & Sundby, 2008; Persson, Winkvist, Dahlgren, & Mogren, 2013). In the few qualitative studies on women’s experience with pelvic girdle pain after giving birth, researchers show that the condition contributes to a difficult life situation for those afflicted (Engeset, Stuge, & Fegran, 2014; Wuytack, Curtis, & Begley, 2015a). In addition, Wuytack et al. (2015b) found that women with long-term pelvic girdle pain felt ignored and were given conflicting advice by health professionals. These qualitative studies centered predominately on women in the first one or two years after giving birth. However, in one study, the researchers explored the experiences of 9 women who had pelvic girdle pain ranging from 2 to 13 years after giving birth (Gutke, Bullington, Lund, & Lundberg, 2017). Gutke et al. (2017) focused on the women’s adaption to pain, and identified two typologies of pain adaption. The women in the first typology tended to struggle against the pain in their effort to adapt to the situation. Despite their impairment, they competed against their bodies and ignored the pain, as they wanted to live normal lives and be physically active like they previously had been. The women in the other group had changed their lifestyle and habits in their adaptation to and acceptance of the situation. Women within this typology had developed an increased bodily awareness, learned to listen to their body’s signals, and changed their behavior.

The authors of a recent Norwegian report on women’s health describe how women suffer from unexplained medical ailments and diseases more often than men (Kilden kjønnsforskning og Norske Kvinners Sanitetsforening, 2018), in line with findings from a prevalence study conducted by Steinbrecher, Koerber, Frieser, and Hiller (2011). Further, we know from Norwegian political documents that women with long-term

conditions have limited access to resources and societal participation (Norwegian Ministry of Health and Care Services, 1999) and that they are over-represented in terms of illness-related work absence and experience a higher prevalence of pain in long-term conditions compared to men (Norwegian Ministry of Children and Equality, 2015–16). With regard to the present study, the researchers' own preconceptions of and experiences with issues related to women's health were important. As researchers, we have a special interest in gendered research and research related to long-term conditions and healthcare. Furthermore, all three researchers are nurses, and the second author has experienced pelvic girdle pain herself. Our experience with and concerns about questions of women's health center around the current lack of knowledge about promotion, rehabilitation and treatment of women's health challenges: specifically, challenges connected to pregnancy and birth—central health questions in women's lives—and the prevalence of “unexplained” medical conditions among women.

In this study, we investigated the situation of women with pelvic girdle pain one year or more after giving birth within the context of their lives: our aim was to explore how women with long-term pelvic girdle pain experience their life and life-world, and how they cope with the situation in their daily life.

Methods

The study has a qualitative design, using open-ended interviews and a phenomenological analysis based on Merleau-Ponty's (2002) epistemological assumptions in order to explore life-world-experiences. Long-term pelvic girdle pain is a relevant life-world phenomenon involving women's cultural expectations of motherhood, family and working life. Therefore we decided to conduct an explorative qualitative study, using individual qualitative semi-structured interviews to obtain a phenomenological description of the women's life-world.

Recruitment and participants

We sought to find women who could retell their experiences descriptively, so we could access the essence of their subjective experience (Kvale & Brinkmann, 2009). In order to reach women with experiences with long-term pelvic girdle pain after giving birth, we contacted the Norwegian National Association for Women with Pelvic Girdle Pain (LKB)—a special interest group for women with such challenges that is a member organization of The Norwegian Association of the Disabled. As of 2018, LKB had close to 900 members.

We searched for a strategic sample of women who had experienced pain for more than one year after giving birth, and who could provide rich data in their variation, including how many years they had had pelvic girdle pain, their level of disability, their experiences with different kinds of treatment, and their working life. The leader of LKB sent an email about the project to all members of the organization in Eastern Norway with an invitation to participate. Nine women contacted the second author, as they wanted to be interviewed. The 9 women were between the ages of 26 and 56, and they had between 3 and 20 years of experience with pelvic girdle pain. They were all ethnic Norwegians and each had completed higher education and had been trained as teachers, nurses, occupational therapists, police officers, or IT professionals. Five of the women lived with their child's father, two had new partners and two were single. Three of them worked full-time but needed some adaptation to manage their working life. Three worked in 30–40% positions and needed significant adaptation to manage their working life. Three women were not capable of working at all and received disability benefits.

Interviews

An interview guide was developed with themes and questions focusing on how the women experienced pelvic girdle pain and impaired function in their daily life. In accordance with our epistemological approach, we developed the guide to create interviews that would be more of a conversation that circled around the women's stories of the situations, adaptations, and hindrances related to their bodily condition and pain, as well as how they approached these challenges in their everyday life. Questions also focused on the context surrounding the women, including their family, wider network, and societal expectations about working and daily life. While the open approach taken with the interviews might mean that some of the women's reflections about conditions and understandings were not articulated, we found that this approach was important in order to capture other aspects of the women's life-world. The second author—a master's student—conducted each of the interviews, during which she strove to create an open atmosphere, while using the interview guide to help maintain focus. One pilot interview was performed to test out the questions, the study's focus and the technical equipment.

The interviews with the women took place in the women's private homes, according to their specific situation and preferences. In the interviews, the women were engaged, open, and willing to share their experiences with, thoughts about, and reflections on their situation. They focused primarily on the challenges of living with pain and disability and carrying a

vague diagnosis that lacks acknowledgement both within society and among health professionals. The interviewer is a psychiatric nurse with a great deal of experience with the topic and conversation therapy. In some interviews, the women became emotional and began to cry when telling their story. They were asked if they wanted to continue or if the interview should be stopped, as the interviewer felt that it was important to approach the women as a fellow “sister,” not as a therapist. After a brief pause, each of the women who had been crying expressed that they wanted the interview to continue—they mentioned afterwards that they were surprised by their strong emotions.

During the interviews, some women lost their train of thought, and stopped to ask where they were and what they were talking about, needing a kind of reorientation to get into the conversation again. They explained that they had a reduced ability to concentrate and remember details due to the pain. In addition, due to a combination of both pain and tiredness, some women needed to take a break in the middle of the interview, and in a couple of situations the interview was postponed because the informant had a “bad day.” All the informants were invited to contact the interviewer following the interview if they wanted to talk. The 9 women were each interviewed once, with the interviews lasting between 60 and 90 min. All interviews took place in 2014, and were recorded and then transcribed verbatim in an anonymised transcript.

Research ethics

The women who volunteered to participate in the study as informant received written information about the study, and they signed an informed consent document. As informants, the women were guaranteed anonymity and the opportunity to withdraw from the study at any time, without consequences. They all agreed to having their interviews recorded, and the Norwegian Social Science Data Services approved the study.

As ethical practice in interview situations involves an awareness of the informants’ vulnerability, we were mindful of the fact that people living with long-term pain and impaired functioning might be understood as vulnerable. The interviewer thus sought to balance the goal of obtaining rich, qualitative data with protecting the informants and securing their safety and comfort—a process that demanded both reflection and respect (Eide & Kahn, 2008).

Analysis

The authors read the transcriptions and met for discussions and reflective dialogs several times during the process of analysis. While reading the

authors were attentive and open to identify meanings and themes. With the goal of identifying the key elements of the women's experiences of living with long-term pelvic girdle pain, we focused on the women's understanding and meaning-making of their situation. Our analysis was aimed at reflecting on and deepening our understanding of the women's experiences, to identify the themes in their accounts and capture the essence of their daily life with pelvic girdle pain. Our analytical process was inspired by van Manen (1997) and his description of determining themes as experiential structures. In our search for themes, we looked not just for common experiences but also for variation. This analyzing process took place in meetings attended by all of the researchers, as well as in continuous dialogs through reflections notes. According to Merleau-Ponty (2002), we must refrain from our taken-for-granted understandings and from what we already know. Thus, we strived for a phenomenological attitude to explore the essential meaning of the women's experiences. This analyzing process resulted in four main themes as findings in the study:

- A life with pain and an unpredictable body
- An identity as disabled, dependent and ashamed
- Recharging on the sofa: adaptation and fighting for dignity and acceptance
- Striving to live as you wish: isolation and working life

Results

The women's lifeworld was colored with pain and disability, influencing family and social life. The women carried a heavy burden in that they struggled with a controversial diagnosis that had only limited acceptance. These aspects were further informed by attitudes related to the moral and cultural norms of contemporary society.

A life with pain and an unpredictable body

The women in our study described an everyday life influenced and partly governed by pain and disability. A life with pain was unexpected, and not in line with their expectations about motherhood and starting a family. The pain made motherhood complicated, as the simple tasks of caring for a baby—such as carrying the baby and changing nappies—became challenging. As new mothers, they found themselves having to live within a small radius, remaining on one floor of the house, with all necessary equipment close by. Some described how they had become slowly aware of the persistence of pain: as time went on following the birth, the pain appeared more

clearly and they became aware of the fact that the pain had not left. Indeed, on the contrary, it was actually limiting their daily activities:

The first three years, when I was at home with the kids, it all was a little foggy. I was first aware of my pain when I was supposed to go back and start working again. It took me a couple of years to realise that my pelvic was still quarrelling, that I was still not OK. Sunniva (16 years with PGP)

As the pain did not go away, the women experienced their everyday situation as challenging. Activities that they had previously taken for granted became complicated and painful and they tried to avoid them:

Standing in a queue, for example, is awful. Sitting is difficult as well. It has been challenging to understand, and to make people at home and outside the house understand that I cannot sit on a chair. Therese (11 years with PGP)

The pain limited their ability to take care of the house—for example cleaning, Hoovering and cooking—making them dependent on their partners and other family members. Challenges and restrictions related to different activities became part of their life, in addition to the uncertainty related to which burdens and strains the body and pelvis could manage before the pain would get too strong. The body thus became unpredictable:

What I find most challenging is not to be in control of myself. That is absolutely a physical challenge. Not to know how far you can walk, how long to sit before you start getting more pain. You must relate to it in everyday life, and it takes a lot to think about how to master this challenge. It is so unpredictable not knowing when you have done too much or had too much strain. Selma (3 years with PGP)

The unpredictability is related to experiences of varying pain. The women described how one day's ups and downs were not necessarily the same the next day. Some days they found themselves to be strong, as the pain was in the background. On other days, the bodies and heads were filled with pain, taking all of their attention and energy. In these instances, the pain in one part of the body seemed to capture the attention of the whole body, and accordingly impacted on their concentration. The management of daily activities became a struggle.

The women described a need to rest and take precautions to prevent pain, reducing their ability to follow up with their family, home and working life. The pain challenged their patience and presence, which in turn influenced their self-esteem, family life and network:

Ultimately I felt like a burden to everyone. I was a burden at home, and a burden at work. I didn't manage anything. They told me I had to take care of myself, because nobody else did. Nobody thanks you. It was difficult after my first child, because I was new in my job. You don't want to be a grumpy young woman who doesn't cope in your life. You know, I am not the first or last woman to have a child. Alexandra (3 years with PGP)

An identity as disabled, dependent and ashamed

For the women in our study, not having the energy to participate the ways they wanted to with regard to their home, family life and network was difficult. They described a strong desire to manage things independently, but instead they felt dependent on other people:

You can't go shopping or go for a walk with the baby in a pram. These years were not normal. Others had to take my daughter for a walk. It might be the neighbour, grandparents, a friend, or my husband who worked full time. Celina (19 years with PGP)

The women's pain and disability affected the interactions with family members, especially in their relationship with their partners. The situation created tensions and uncertainty in the family:

It has been very demanding regarding family life. I have been lying on the sofa, to relax and just doing some small exercises. The great burden was on my husband—it was too much for him. I did not understand completely how he felt until later. It was hard to communicate, and we needed consultation, family therapy. They reminded me that my husband had a full job and that when he came home, he had to take care of all the housework. It is not 100 per cent on him, but 150 per cent. The scale was unbalanced. I realised that I couldn't expect him to follow up on my terms, the housework had to be done but on his terms. It was a revelation for me. Our relationship was bad—much quarrels, typically about housework. Linnea (4 years with PGP)

In the interviews, the women related the guilt they felt in their relationships in terms of not fulfilling expectations as a mother and a wife. Furthermore, they describe how the situation impacted on their relationship and interactions with their child. A common expectation they voiced is that a mother should be able to take care of her child and her children's interests:

She hasn't been so much on the playground together with the others as a little child. I couldn't follow her or run after her if she ran out into the street or things like that. So sometimes I am a bad mother. Therese (11 years with PGP)

The women explained that they feel inadequate in their families, and that their disability creates feelings of distance with their child. For example, because of the pain, they were unable to come down to their child's level, to play with the child on the floor. The women also tell how, early on, their children had to help with household chores because of their mother's disability, for instance emptying the dishwasher, and hanging up clothes to dry. They related how they felt that, due to day-to-day variation in their pain, their children found it difficult to understand why an activity that was possible one day was impossible for their mother the next day. As family life generally involves the expectations that families want to spend time together, extra time together is normally seen as a bonus. For the

women with pelvic girdle pain and disability, family life on weekends and holidays could be challenging.

I never get holidays or weekends—it's silly of me to say, but they are the worse days. Then I stretch a little extra. I always feel bad after holidays. Midway in the holiday, everything unravels. It is because I want to participate, and I do not get as much rest as I need. I can lay down on the sofa or my bed when the others are there, but I don't because I want to be with them. So, I don't get the opportunity to get a grip on myself. Aurora (13 years with PGP)

Some denied their pain and pushed themselves to participate in activities even though it led to more pain, because they found it hard to accept their situation.

My thing is that I have ignored the pain, and I just kept on and didn't care. That was not so smart. I have destroyed myself because I have pushed too much—some of the reasons why I am so bad today. It is my own fault. I have pushed, and pushed to be a good girl, and gone far beyond the pain threshold. Isadora (20 years with PGP)

The fact that the women still experienced pain as time passed without a cure meant that they found themselves needing to accept themselves as a disabled person—a process that was painful to their identity. In the public space, they experienced visual bodily dysfunction as shameful:

I do not like to see myself as handicapped, but I am. I've got a parking card for the handicapped, but I don't keep it up on the front shield. I hide it within the glovebox, for this is not me. I use it when I need it, but I don't use crutches. That make people stare at me, and it is frowned. Christina (26 years with PGP)

Recharging on the sofa: Adaptation and fighting for dignity and acceptance

In different ways, the women tried and struggled to adapt to their new situation of pain and disability by searching for new ways to control and manage the pain:

You have to start again, and you must learn it all to master it on the way.

Therese (11 years with PGP)

The women described a need to rest, plan and prepare for activities in order to be able to complete them. The sofa in the living room became their 'commando central', where they could lay down and rest their pelvis while at the same time follow up with their life and family:

The sofa is my base in daily life. I get up to do errands, and when my pelvic aches, I get back on the sofa to recharge. It's very important not to overdo my capacity.

Isadora (20 years with PGP)

The women detailed how the planning of activities was vital to managing daily life; this also involved prioritizing activities, use of painkillers and

time to rest. A significant focus in their lives was related to expectations about women, especially concerning domestic work. They described feeling a great responsibility to create a respectable and tidy home—for example in case guests were to appear—but they found they needed to ease back on these expectations:

Cleaning windows four times a year is impossible in periods when you can hardly stand for a quarter of an hour. You also feel depressed, when it is constantly dirty and dusty all around the house. Dirty windows and so on. You just have to accept that, this is how our home is like. It just has to be like this. Sunniva (16 years with PGP)

Considerations regarding openness about their situation, and how much to explain about the situation and limitations to friends, were difficult for the women, and involved feelings of vulnerability. They felt it demanding to make people understand how the pain impacted on their ability to take part in social activities:

Usually I don't mention things to my friends. I adjust appointments and cancel if I have a bad day. I'm not sure if my friends understand that my pelvis bothers me, it's somehow nothing I talk about. If I have to explain that I am in pain and why I'm in pain, what I can do and what I cannot do; to me it's vague. I cannot pinpoint what is right for me or not. I know I shouldn't stand or sit, but that's all. It's not easy to explain. Selma (3 years with PGP)

Some of the women we interviewed reported needing aids, such as crutches and pillows. Painkiller provided relief on some days, so that they could be active and take part in activities. However, many women described how they had to rest after an active day, as they “cannot surf on the top of pain one day after another” (Isadora, 20 years with PGP)

Several of the women explained that physical activity and treatment could ease the pain and make them feel better. Some did exercises guided by physiotherapists on how to use and move their bodies in new ways to reduce symptoms and avoid provoking pain:

When it comes to how to use your body, you have to collect hints and the physiotherapists are good at that in everyday situations. Do not push, shove, carry, hold—tips about what not to do. To stabilise the pelvic floor doing exercises, was the turning point. It was possible to build it up, and get a little further. Celina (19 years with PGP)

The women experienced limited knowledge and interest among health professionals', which was frustrating and they connected this to the lack of a diagnosis. The lack of objective measures were experienced as challenging, leading to uncertainty and a feeling of not being believed. They described their fight for acknowledgement of pelvic girdle pain as a diagnosis:

I think it would be easier if one could take an X-ray and say, “Yes, look, here is a proof of your pelvic girdle pain—this is a challenge you will have to live with for the rest of your life.” Then you can relate to that, and you would know exactly what the problem is. It’s not about me being lazy or having a low threshold for pain. I think it would have been easier if the pain had been constant and it could be detected. Therese (11 years with PGP)

The women searched for information in different places and found that much of the information they received was conflicting or incorrect. Some of them reported that their lack of improvement was frustrating for their GPs, which ultimately gave the women no other option than to apply for disability benefits. The health professionals’ uncertainty and limited treatment opportunities thus contributed to making a difficult situation even more desperate. For some women, the situation affected their mental health such that they needed consultations with professionals to handle and master the situation.

Striving to live as you wish: Isolation and working life

We have seen that life with long-term pelvic girdle pain and disability impacts women’s participation in social life and family activities. To manage participation in various activities, however, thorough planning is necessary in order to reduce and prevent pain. The women in our study explained that it takes significant energy to participate in activities and to invite people over, resulting in social life that has been stripped down.

I’m fed up with the pain, and not being able to live as I wish. It limits my daily life and I have lost many friend because I lie in bed. I have not been social, not gone out to meet others. I haven’t invited people to our home because I haven’t managed.

Alexandra (3 years with PGP)

In the interviews, the women explained how this kind of situation results in isolation. One side of this relates to physical abilities—for example, inviting friends over for a cup of coffee may be demanding. Another side they described is that people do not understand:

I will not show all people how I am, it’s so hard. Therefore, I switch over to, what should I say – I live in a lie. I know of my situation myself, but I haven’t managed to show others because it’s tough. Celina (19 years with PGP)

The women expressed vulnerability related to their situation. It was hurtful to them when others thought they were being lazy. Some had to abandon friends because they did not respect or understand their challenges. The women’s feelings of isolation were also an effect of being unable to return to work. They felt that leaving the home was good for their mental state, even though it was a physical challenge to manage working. This would lead to exhaustion:

I was at work first, then collecting my kid from the kindergarten. Instead of going directly to the kitchen and starting to make dinner, I needed 10 minutes on the sofa to ease the tension in my pelvis and be able to move again. After making dinner and getting the kid to bed, I could not necessarily go out or do anything else. Therefore, my social life has suffered. Linnea (4 years with PGP)

Again, we can see that balancing work, activity and rest was a demanding focus for the women—as were societal norms regarding the moral values of participation in working life.

My job takes all my energy. For me, it is so important to be able to tell people that I go to work because it defines me as a human being in society. I am willing to pay that price by working. Those who do not work are met by different attitudes than I am ... Those who don't work and are on social benefits are stigmatised. I am seen as active in working life. Today it is shameful to receive benefits or be on work assessment allowance. Isadora (20 years with PGP)

The women who managed to work part- or full-time described the need to adjust their work environment, as sitting down for long periods of time was impossible. They needed to change positions regularly to reduce pain during their workday, which was not always practically possible and necessitated a cooperative employer. For 3 of the 9 women in the study, working was impossible, so they were on 100 per cent disability benefits. They felt stigmatized and ashamed about not being able to work and being on benefits—but also relief, because they had been so stressed by the feeling that they could not meet the expectations of working life.

Despite complex and long-term experiences of living with pelvic girdle pain, the women in our study expressed a strong hope and belief that their condition would improve. Some felt that they had already become a little better and were eagerly looking forward to further improvement and being able to work more in the future.

Discussion

We have illuminated how women with pelvic girdle pain between 3 and 26 years after giving birth live their lives with painful symptoms and complex challenges related to their disability—these impact their daily life, interactions in their networks, and their identity. Going through a bodily change involving pelvic girdle pain, disability and uncertainty for a long period after pregnancy and giving birth is a phenomenon of experiences carrying life-world meanings. Perspectives on the life-world and the epistemological assumptions of phenomenology points to the particular world of experiences that we know and take for granted, as our life-world is all we know yet it is impossible to know completely (Merleau-Ponty, 2002). In this article, we support and expand the findings of other qualitative researchers in this field (Engeset et al., 2014; Gutke et al., 2017; F. Wuytack

et al., 2015b), specifically concerning how the pain and physical challenges complicate women's daily activities, partnerships, family activities and ability to take part in social and working life. These challenges consequently affect women's ability to live a full life and they experience their situation as complex and distressing.

The difficult situation for these women began with bringing a child into the world, which is generally understood to be a positive life transition, one filled with hope and expectations. In most cultures, carrying and then caring for a new baby is thought of as one of life's highest moments, but also a situation that demands energy, awareness and attention regarding the baby and its needs. Because of pain and impaired function, daily life for the women in our study had become a stressful and painful experience, complicating their interactions and activities with their child. Such challenges are also described by mothers with other kinds of physical disabilities (Wint, Smith, & Iezzoni, 2016). Furthermore, lower general level of well-being is found among women with chronic pelvic pain in a population-based study from New Zealand; pain is connected to fatigue and restricted level activities in daily life (Grace & Zondervan, 2006).

Our study illuminates how the women needed assistance and help from their partners and family members due to their pain. We also found that the women's pains made them dependent on their partner and that this challenged their relationship. Indeed, researchers who have studied patients with spinal or low back pain also point to the strain on patients' relationships with partners and consequences for the family, involving children and family activities (De Souza & Frank, 2011; Strunin & Boden, 2004). Also, in line with our findings, these researchers find that children—once they are old enough—are involved in the household chores. The women in our study described their bodies as unpredictable, with shifting conditions from day to day—for a child it can be difficult to understand his or her mother's variation in pain and energy, and our informants described how this created tensions in their families.

In our interviews, we found that the women experienced shame and threats to their identity, especially when they were unable to fulfill expectations regarding working life. Further, they were hurt by other people's lack of understanding about and/or belief in their symptoms, and this led to isolation. For the women in our study, this represented a great challenge, and added to their burden. The lack of help from the healthcare system represented another challenge for the women. In addition to experiencing pain, the women's reduced ability to return to work led to isolation, and challenged their self-respect, independence and dignity.

The women who took part in this study explained how, over time, they adapted to the symptoms while going through the slow process of

accepting their situation, experiences that are in line with findings from Gutke et al. (2017). As ignoring the pain would bring its own punishment, the women found ways to deal with their long-term situation, involving planning for activities, resting and reducing social and physical activity. These findings are important and serious—in this article, we highlight a group of women that have reduced capabilities for a substantial duration, some for the rest of their lives, because of pregnancy and childbirth. In light of Maurice Merleau-Ponty's theory, we illustrate how long-term pelvic girdle pain challenges the “bodily habits” of the women in our study. According to Merleau-Ponty the “habit body” is the body as it used to be, with previous habits and experiences representing a competence or embodied knowledge, which is challenged in situations of bodily change. In situations of bodily change, the person must relate to “the body at this moment,” where the body cannot be taken for granted and the person must adapt to a new life situation (Merleau-Ponty, 2002).

The women in our study found it challenging that that their pain was invisible and that people did not understand their situation. In focus-groups with patients with low back pain, Bailly, Foltz, Rozenberg, Fautrel, and Gossec (2015) found that the patients felt misunderstood and that people in their network saw their challenges as psychological. Further, the patients had lost their social role, as they had difficulties at work and challenges following up responsibilities at home—as a result they suffered from a negative self-perception. This trend is highly recognizable in our findings. Smith and Osborn (2007) also discuss the negative impact that long-term pain has on the self and its connection to shame. They find that people with pain evaluate themselves in relation to others and situate their self-judgement within a social context. Additionally, people who are ashamed feel powerless and inferior, as well as vulnerable and unattractive (Smith & Osborn, 2007). We certainly found this to be true for the women in our study. This phenomenon might be better understood in light of Merleau-Ponty (2002) work on how the human experience of being in a body is understood as fundamental for being in the world and for the interwoven relationship between the psychic and the physiological body when a body changes—for example after an injury. Perception is not something happening within an individual, but in an intertwined relationship sensing the body and the things of the world. In this way, the body and the world are in a constant “dialogue.” Structures represent bodily, psychological and socio-cultural patterns forming a person's experiences of the world, but also a person's encounter with the world (Billington, 2013). We are tuned into such structures, as integrated ways of understanding and approaching the world, and stable patterns of experience are developed related to how to move, to respond to for example social situations and our ordinary life world (Billington, 2013).

In our study, the interwoven relationship between structures in society and the women's approach to the world reveal traditional gendered expectations regarding the roles and responsibilities of a housewife and mother, and the women's concerns about not being able to follow up domestic work at home. The women also connected their situation and challenges to societal understandings of long-term girdle pain, as it is a diagnosis that has not been medically accepted. Societal conditions and understandings and how these affect people's self-understanding with regards to long-term illness have been illuminated in an ethnographic study from Austria on women with rheumatoid arthritis. Prodingler, Shaw, Rudman, and Stamm (2014) found that women with rheumatoid arthritis wanted to keep their disease invisible and thus wanted to avoid using visible medical devices. The researchers link this to societal and historical conditions in Austria, where health defects were related to unproductivity and increased societal costs, and people to be outside the norm. The authors illustrate how policy is interwoven in the lives of the women with disabilities and explain how the bodily experiences of the women are in an intertwined dialogue with the world around them. A changed and painful body is related to experiences of identity and shame, and a result is that the women with pelvic girdle pain hide their disability, striving to not have attention directed at their disability. Other people's view of them as different creates embarrassment.

In line with Engeset et al. (2014) the women in our study found it difficult to explain their disabilities and to get others to understand their limitations—accordingly, they found that they had to fight to be believed and acknowledged. As a medical diagnosis represents the basis for welfare benefits, a situation of powerlessness and hopelessness arose for the women when they felt misunderstood and suspected. Regulations, criteria and norms are examples of structural patterns influencing the life-world of the women in our study, in this article, we reveal how their bodies are in a “dialogue” with the world around.

Clinical implications

We found that the women in our study are living in a difficult situation, one that leads to frustration and powerlessness. We see a need to improve the state of knowledge about long-term pelvic girdle pain after giving birth; our hope is that health professionals—e.g., medical doctors, midwives, physiotherapists and nurses— work towards uniform criteria and a memorandum of understanding regarding long-term pelvic girdle pain after child-birth. This would provide a basis for developing a clear protocol concerning treatment and behavior that may help women with this condition.

In addition, acceptance of the condition is important with regard to the women's relationship with the social security system, and their opportunities to adapt to working life. A focus on increased societal recognition and acceptance of disability in order to reduce shame and stigma would highly benefit these women.

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