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## A limited life – a mixed methods study on living with persistent pregnancy-related lumbopelvic pain more than 12 years postpartum in Sweden

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### ABSTRACT

**Purpose:** The scope of this study is women's descriptions of symptoms experienced through persistent pregnancy-related lumbopelvic pain (PPLP) as well as their strategies to cope with the condition.

**Methods:** This is a mixed-method study based on questionnaire responses and inductive interviews with 12 Swedish women with self-reported PLP during pregnancy 2002 partaking in a 12-year postpartum follow-up questionnaire cohort. Test of statistical differences between the interview cohort and the total cohort was performed and the interviews were analysed through inductive qualitative content analysis.

**Results:** The questionnaire data showed that the interview sample reported significantly more pain than the questionnaire respondents but resembled the questionnaire respondents on most other characteristics. The theme "*Balancing avoidance and activity*" and its sub-themes illustrate the strategies the participants used to manage their situation on a daily basis. The pain was a constant reminder that led to evaluation of pros and cons for physical, social, and mental activities as well as the search for therapies and treatments.

**Conclusions:** For the women who participated in the interviews, living with persistent pregnancy-related lumbopelvic pain caused limitations and negatively affected various and major parts of life to a far greater extent than previously known.

### ARTICLE HISTORY

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### KEYWORDS

Persistent pregnancy-related lumbopelvic pain; interview; mixed-method; follow-up; pelvic girdle pain

### ► IMPLICATIONS FOR REHABILITATION

- Persisting pregnancy-related lumbopelvic pain affects various and major parts of life, including working, physical and social activities, and psychological well-being.
- Rehabilitation should focus on individualized physical activities and effective coping strategies.
- Effort should be put into helping the patient find fulfilling explanatory reasons for the persisting pregnancy-related lumbopelvic pain.

## Introduction

Pregnancy-related pelvic girdle pain (PGP) and/or low back pain (LBP) are common health problems affecting 24–90% of pregnant women [1]. The wide range can in part be explained by the differences of definition in different reports [1,2]. At present, PGP is defined as pregnancy-related pain between the gluteal fold and the posterior iliac crest, especially in the proximity of the sacroiliac joints (SIJ) [2]. The pain can be continuous or recurrent and experienced concomitantly with/or exclusively as pain in the pelvic symphysis, radiation of pain can also occur into the posterior thigh. The aetiology and pathological mechanisms of PGP are uncertain; mechanical, hormonal, metabolic, traumatic, and degenerative causes have been proposed as possible causes [1,3]. For undiagnosed symptoms in this region with no differentiation between PGP and LBP the term lumbopelvic pain (LP) is used [3].

For most women, pregnancy-related LP (PLP) is a self-limiting condition [3], however, as we have previously reported, for some women symptoms are both persisting as well as physically and psychological disabling [4]. Symptoms of PLP have been shown to persist from 6 months up to 12 years postpartum, with prevalence

ranging from 4% to 31% in different studies [5–11]. We have previously reported that persistent PLP (PPLP) has a negative impact on self-reported health and daily living activities at 14 months as well as at 12 years postpartum [5,6] and women with PPLP commonly report multiple pain sites [6].

PPLP may influence many aspects of life, to date few qualitative studies have been conducted investigating the long-term effects in women experiencing PPLP [12–14]. A deeper understanding of the phenomenon of living with PPLP may be achieved by combining quantitative and qualitative data. Thus, we aim to shed more light on patients' specific experiences of living with PPLP more than 12 years postpartum by combining quantitative survey results and qualitative inductive interviews. The scope of this study will be women's descriptions of symptoms experienced through PPLP as well as their strategies to cope with the condition.

## Method

### Design and setting

This is a mixed-method study based on initial questionnaire responses adding inductive interviews with a sample of women

partaking in a 12-year postpartum follow-up questionnaire cohort of women reporting LP during pregnancy, 2002 in Sweden. The primary quantitative data collection took place between 2002 and 2003 through three questionnaires (Q1–Q3) at three time points; Q1 in connection to delivery in 2002, Q2 at 6 months, and Q3 14 months postpartum. We have described earlier data collections (Q1–Q3) in detail elsewhere [5,6,15].

For this study, a Quantitative → Qualitative sequential design was applied to deepen and augment the experiences in a sub-sample of women with continuous or recurrent PPLP [16]. The fourth follow-up questionnaire (Q4), with similar questions posed in previous Q1–Q3, was sent out in late 2014 to early 2015 to the cohort. The Q4 data provided a background of pain-related outcomes which assist to identify a sub-sample of potential participants to invite to the qualitative part of the study. An inductive approach (i.e., data-driven) was used for the interviews to gain a deepened theoretical understanding of the participants' experiences without applying any specific theoretical perspective in advance.

### Participants and recruitment

At approximately 12 years postpartum (i.e., late 2014–early 2015), Q4 was sent out to the 624 women who were contactable from the initial cohort ( $n = 639$ ). A total of 295 women responded to Q4 rendering a response rate of 47.3%. Detailed information of women responding to Q4 has been published elsewhere [6]. Thereafter, the quantitative data from Q4 helped to identify a purposive sample of women reporting continuous or recurrent LP to be invited to interviews. Inclusion criteria for the interview study were self-reported continuous or recurrent LP in Q4, living in the city of Luleå in Sweden, or any of the communities in its vicinity, aged less than 64 years, and having the ability to communicate fluently in Swedish. Exclusion criteria were: current pregnancy, acute trauma during the 12-year follow-up period, any diagnosed disease such as cancer, serious infection, cauda equina syndrome, fibromyalgia, osteoporosis, vertebral fracture, diagnosed disc herniation, and disc surgery, spinal stenosis, or any ongoing insurance claim. All eligible participants fulfilling the inclusion criteria received oral and written information regarding the interview study prior to inclusion, including information about voluntary participation and integrity of their personal data. Fourteen of the nineteen women invited to participate were interviewed. Two interviews, however, were excluded resulting in 12 participants (see "Data collection" section for further information about excluded interviews). A signed consent was obtained from all participants prior to the interviews.

### Data collection

A detailed information about Q4 and the quantitative data collection is presented elsewhere [6]. In sum, the Q4 covered question regarding health outcomes and validated instruments addressing health status, quality of life, disability, and pain.

A semi-structured interview guide was developed to aid the interviews, but the participants were also allowed to focus on subjects most importance to them. A brief summary of the interview guide is presented in Table 2.

Interviews were conducted in January–March 2016 and in all cases the interviews were performed at the office of the second author by the second (CB) and fourth (MP) author. The interviews were digitally recorded with the consent of the participants and lasted 30–90 min. The interviews were thereafter transcribed

verbatim. Two interviews had to be excluded from the analysis one as the participant could not provide any detailed information about her situation due to language problems that were detected during the interview, and the second due to technical issues of the recording device that did not enable transcription, resulting in complete data from 12 women.

### Definitions

At the time of the primary data collection in 2002 (Q1), there was no consensus on the definition of PGP. The prevailing definition of PGP was then self-reported continuous or recurrent pregnancy-related pain in an area depicted in a picture that was attached to Q1–Q4 (Figure 1) [15]. Persistent pregnancy-related lumbopelvic pain (PPLP) was defined as continuous or recurrent PLP the past 12 months at the time of filling out the follow-up questionnaire.

### Analysis

#### Questionnaire data

Pain intensity was reported in Q1–Q4 using a Visual Analogue Scale (VAS) with endpoints at minimum 0 mm responding to no pain, and maximum at 100 mm responding to worst imaginable pain [17] and was presented as means. Other variables used for the quantitative analysis were age, number of children at Q1 and Q4, which were presented through descriptive statistics. Body mass index (BMI) was calculated using the formula kilograms/(height in meters)<sup>2</sup> at Q4. Educational level (Q1) was based on the following response options: elementary school, high school/folk high school, and university. Sick leave in the past 12 months, granted disability pension, and prescription and/or non-prescription drugs were self-reported descriptive data from Q4. Descriptive statistics were used and to test for difference between groups, the independent Student's *t*-test was used for continuous variables and Pearson's Chi-Square test for categorical data, as appropriate.

#### Qualitative analysis

The analysis of the interviews used inductive qualitative content analysis [18] which is a suitable method to systematically explore manifest and latent differences and similarities in data.

As described by Graneheim and Lundman [19], the first step was familiarisation with the data through repeated reading of the transcripts and identifying content areas. Thereafter, all transcripts were coded, the codes were short phrases representative for the meaning in the transcripts and corresponding to the aim. Further, codes were compared for similarities and differences, forming categories, and sub-themes. During this process of moving from the

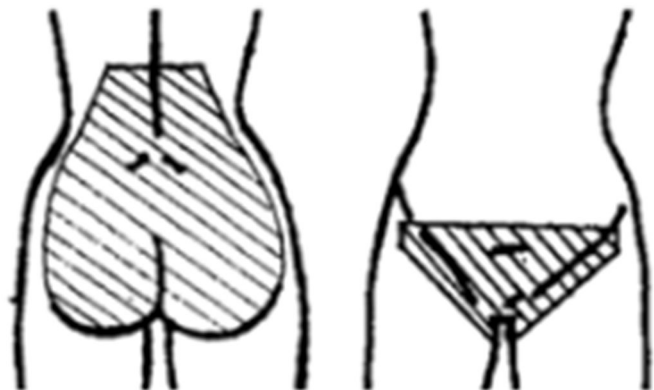


Figure 1. Pain-drawing used in the questionnaires Q1–Q4 [15].

concrete (codes) to more abstract levels (categories, sub-themes, and theme), repeated discussions among the first, second, and fourth author were performed to challenge any pre-understanding, secure objectivity of data and obtain consensus in the analysis. In the final step, the theme emerged illustrating how women with PPLP experience their current situation; that is, the latent meaning running through the data. The final result was discussed and approved by all authors.

Ethical consent was approved by the Ethics Committee at Umeå University. (Dnr 2014-4-32M supplement to Dnr 2012-404-31M) and all steps of the research process were performed in accordance with the Declaration of Helsinki.

## Results

### Participants

Table 1 presents characteristics of participants. Four of the 12 participants reported having given birth after the baseline pregnancy in 2002. A comparison of the selected 12 participants and the 237 participants from Q4 (Table 2) showed no significant differences between groups apart from the study participants reporting significantly more pain (in line with the inclusion criteria).

### Description of symptoms more than 12 years postpartum

#### Pain – quantitative measures and qualitative descriptions

The interviews confirmed that pain was the main symptom among the participants and that the pain was primarily localised to the lower back and groin region, and radiating towards the hip socket, trochanteric region, and thighs. Sample characteristic of the interview participants, compared to other Q4 respondents, showed significantly higher pain intensity the past week, where participants in the interviews reported self-reported pain rating scores of VAS 55.3 mm (SD 25.9) vs. VAS 30.0 mm (SD 29.3) among Q4 responders ( $p = 0.004$ ).

Pain was commonly reported in the thoracic spine and neck and two participants described pain in the entire body. All interview participants reported sciatic pain ( $p = 0.002$ ). Additionally, neck or thoracic spinal pain was also commonly reported, although not demonstrating a statistically significant difference (Table 3). One participant described symptoms not exclusively coherent with PPLP in her interview, nonetheless, all participants stated that their pain condition had begun during their pregnancy in 2002.

Generally, the participants described how the characteristics of the pain had changed over time. During pregnancy and puerperium, the pain was recalled as being sharp and stabbing while about 12 years later, the pain was experienced as a dull ache that

intermittently could become sharp and/or stabbing in nature, mostly related to certain movements or activities. Further, the women found their muscles in the lower back and buttocks as being tired, stiff, and tight. Participants also experienced stiffness or locking in the hip joint. Sensations of numbness and tingling in legs and feet were described by four participants. The pain increased by movements such as bending forward, rotation of the back, abduction of one or both legs, or lifting light or heavy objects. Persistent repetitive movement, such as taking long walks, could also intensify the pain. Too little physical movement, that is, not exercising, but also sitting for long times, or sleeping in a bed that was too soft or too hard could aggravate symptoms. Five participants reported using prescription/non-prescription drugs (antidepressants, non-steroid anti-inflammatory drugs (NSAIDs), paracetamol and opioids) on a regular basis.

### Secondary symptoms

Secondary symptoms had developed over time, and physical and mental tiredness as well as exhaustion were described. Two participants said that “the pain” itself caused tiredness, and four participants said they were tired because they had their sleep quality reduced by pain.

*The pain interferes with my sleep. I have difficulty moving and I become stiff, that kind of thing. I need to get several hours of sleep, but still I don't feel rested.* (Participant 9)

Four participants revealed present or previous feelings of feeling “blue” and/or had clinical depression which they related directly or in part by their pain condition.

*Tiparol® is the drug that has the best effect on my pain, I take them every week, but they make me depressed, I feel as I am worthless, and I question why I am here.* (Participant 8)

### Qualitative analysis – “balancing avoidance and activity”

The theme emerging from the inductive qualitative analysis was, “Balancing avoidance and activity” and its sub-themes, “Searching for solutions to manage pain” and, “Assessing and controlling the situation” illustrate the different strategies the participants used

Table 2. Overview of main topics included in the interview guide.

- How has the lumbopelvic pain (LP) developed since 2002?
- In general, how do you look upon LP after delivery?
- What consequences has LP given you since 2002?
- How do you experience the support and understanding given regarding LP?
- How do you look upon the future?
- Is there something you find important, that have not been addressed? Please, tell

Table 1. Descriptive information of participants.

Participant	Age at Q4	Number of children at Q1	Number of children at Q4	BMI <sup>a</sup> at Q4	Highest educational level at Q1
1	43	2	3	27.1	High school
2	46	2	2	30.8	High school
3	41	1	1	20.5	High school
4	39	1	1	22.5	University
5	46	1	1	46.2	High school
6	53	2	2	18.6	High school
7	39	2	2	20.5	University
8	43	1	1	28.7	Elementary school
9	36	2	3	22.2	High school
10	42	2	2	22.3	High school
11	38	3	4	18.7	High school
12	41	1	3	21.8	University
Mean (SD)	42.3 (4.7)	1.7 (0.7)	2.1 (1.0)	25.0 (7.7)	

<sup>a</sup>Body mass index (kg/m<sup>2</sup>).

**Table 3.** Characteristics of the interview sample and the other participants of Q4 using Student's *t*-test and Fischer's test for small samples.

	Q4 participants not participating in interview <i>n</i> = 283	Interview sample <i>n</i> = 12	<i>p</i> Value*	
			Fisher's exact test	Student's <i>t</i> -test
Age in years at Q4, mean (SD)	43.4 (4.6)	42.3 (4.7)		0.78
<i>Marital status</i>				
Single	2 (1.0)	0	1.00	
In a relationship	278 (99.0)	12 (100)		
<i>Highest level of education</i>				
Up to high school	142 (51.3)	9 (75.0)	0.14	
College or university	135 (48.7)	3 (25.0)		
Additional children after Q1	154 (54.5)	4 (33.3)	0.24	
Total number of children Q4, mean (SD)	2.3 (1.2)	2.1 (1.0)		0.24
Body Mass Index (BMI) at Q4, mean (SD)	25.6 (5.1)	25.0 (7.7)		0.70
Pain intensity the past week (VAS <sup>a</sup> ), mean (SD)	30.0 (29.3)	55.3 (25.9)		0.004
Pain intensity the past 12 months (VAS <sup>a</sup> ), mean (SD)	51.0 (23.9)	64.3 (24.6)		0.06
<i>Neck or thoracic spinal pain past 12 months</i>				
No	86 (45.7)	5 (41.7)	1.00	
Yes	102 (54.3)	7 (58.3)		
<i>Sciatic pain</i>				
No	79 (42.5)	0	0.002	
Yes	107 (57.5)	12 (100)		
<i>Sick leave the past 12 months</i>				
No	159 (87.8)	8 (66.7)	0.06	
Yes	22 (12.2)	4 (33.3)		
<i>Granted disability pension</i>				
No	166 (93.3)	11 (91.7)	0.58	
Yes	12 (6.7)	1 (8.3)		
<i>Prescription and/or non-prescription drugs</i>				
No	153 (54.6)	7 (58.3)	1.00	
Yes	127 (45.4)	5 (41.7)		

Numbers in parenthesis are percentage unless otherwise specified.

<sup>a</sup>Visual Analogue Scale in millimetres.

\*Significance test *p* < 0.05.

**Table 4.** Overview of findings from the qualitative analysis.

Categories	Subtheme	Theme
Underlying feelings	Assessing and controlling the situation	Balancing avoidance and activity
Creating own understanding of the condition		
Avoiding activities		
Paying the price		
Having a variety of treatments	Searching for solutions to manage pain	
Adjusting ways to move		
Changing jobs		
Achieving social support		
Planning ahead		
Using different aids		

to manage their situation daily. The pain was a constant reminder that led to planning and extensive weighing the pros and cons for physical, social, and mental activities as well as the searching for different therapies and treatments. Pros covered everything positive with the alternative at hand, cons led to increased pain and other additional symptoms; that is, a perpetual balancing between avoidance and activity to manage each situation.

An overview of the qualitative findings is presented in Table 4. Sub-themes and their corresponding categories are presented below together with illustrative quotes from participants.

#### *"Assessing and controlling the situation"*

The sub-theme "Assessing and controlling the situation" describes the decision-making and cognitive assessments the participants made of any situation that caused or potentially could cause an

increase in symptomatology to remain in control. This sub-theme covers the following categories: *Underlying feelings; Creating own understanding of the condition; Avoiding activities; Planning ahead and Paying the price.*

***Underlying feelings.*** A wide spectrum of negative feelings was identified in the interviews, most narratives contained expressions of sadness, fear, worry, and guilt. Sadness was expressed in relation to suffering from pain and missing out or not being able to contribute because of the pain or fear thereof. Fear and worry were expressed in contexts of imagining the future, a deteriorating pain situation, and not being able to work or take care of oneself. Feelings of guilt was expressed related to the notion that they may have contributed to their condition by not taking enough care of their own physical health.

*I am a caring, loving person, I love to hug people and show them how much I care. But I can't even hold a little baby, I can't lift my daughter to hug and to hold her, and I never could. It makes me sad; I don't feel like a whole person. (Participant 8)*

***Creating own understanding of the condition.*** Every participant had her own set of explanations to what caused the longstanding pain. These explanations appeared to have a great impact on how the participant acted on and reacted to the symptoms. The most common explanation was being in poor physical shape at the time of the pregnancy or labour, or at the time of the interviews. Poor physical shape was related to have "weak abdominal and short gluteal musculature".

*I think that I would have had less problems if I had been better at exercising. When I just had my baby, my abdominal muscles were so weak I think that's why I got so many problems. (Participant 6)*

Some participants found that hormonal levels had an impact on their symptoms with increased symptoms in the ovulatory phase and the bleeding period of their menstrual cycle. Other explanations to prolonged problems were; a new pregnancy close to previous delivery, mode of delivery (both caesarean section and vaginal delivery were mentioned as explanations), giving birth to a macrosomic child, having preterm labour, instability of the pelvic girdle, pelvic and spinal misalignments, being of older age, inflammatory status of the body, stress and posing high demands on oneself; that is, illustrating a variety of explanations related to their prolonged problems. Deciding to become pregnant again before the resolution of the pain from earlier pregnancy/pregnancies and a notion that the pain was strongly related to pregnancy, lead to the conception that one had to choose between having children or having no pain.

*I guess it's unlucky that I'm still in pain, but if the choice is between having children or no pain, the decision is easy, I actually got one more child, who is five years now. (Participant 11)*

Participants' own understanding of the understanding of their choice of solutions interacted, such as the use of a SIJ stabilizing belt if pain was due to instability of the pelvic joints. Beliefs of musculoskeletal misalignments causing the pain prompted some participants to seek chiropractic or naprapathic treatment. NSAIDs were the drug of choice if inflammation was believed to be the cause of pain. The participants readily rejected that their symptoms could have a psychogenic component.

**Avoiding activities.** Avoiding activities was often used as a strategy to minimize momentary excessive pain or fear of increased pain. The inability to harbour feelings and sensations of fear and/or excessive pain, left the participant with no control of the situation and thus, the only feasible choice was to avoid the activity itself. Fear of pain mainly derived from the inability to cope with more pain due to increased symptoms, and additional damage or trauma to any part of the body was dreaded.

*I avoid certain activities like downhill skiing and horseback riding, I would not dare the risk of falling and cause more damage to my body. (Participant 5)*

Some participants described avoiding activities that might make other people question whether the problems they experienced were real. Consequently, these participants consciously or unconsciously tried to keep up with the role of being a person in pain.

*If I was in town, I thought that people did not believe that I was in pain. It was as if I couldn't enjoy myself, because then people would not believe me. (Participant 7)*

**Planning ahead.** All participants revealed a number of arrangements taken and how they always planned ahead to diminish situations where the pain could be aggravated. Those arrangements covered a wide range from choosing the "right" shoes, to making plans and arrangements for future housing and living conditions in case the physical mobility would be negatively affected.

*"I always think about what kind of shoes I wear and how the interior is where I am going, will there be a place for me to sit to put them on in case I take them off? I think of how I carry things, what bags I can use. I think about where I can live when I grow older if I get more pain. I think about it and plan for it all the time, because I am always in pain" (Participant 2)*

**Paying the price.** The fact that certain activities came with a price-tag in terms of increased pain was evident. Choosing to

perform an activity that caused or potentially could cause increased symptoms was dependent on the situation and the participant's perception thereof. Things that were important to the participants either as going to work and making a living, or things that were close to heart were more likely to be prioritized despite the increased pain.

*One-time last year I had to dig the car out from lots of snow, and there was no one there to help me so I did it all by myself. Immediately I got more pain, and it got worse the following hours. (Participant 5)*

*In periods of increased pain, I do nothing. I go to work and do what I have to, then I go home to rest. (Participant 8)*

### "Searching for solutions to manage pain"

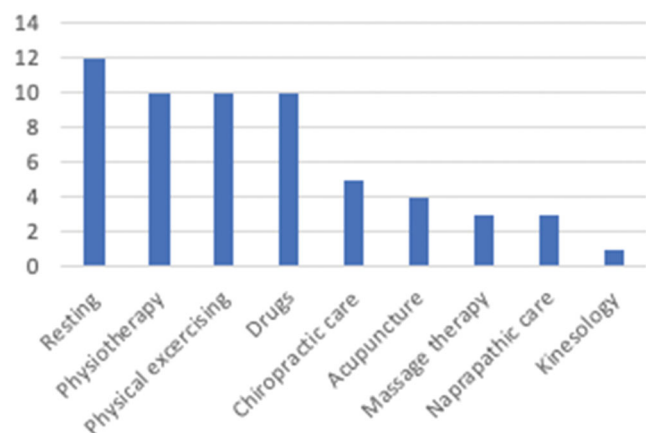
This sub-theme demonstrates how the participants constantly tried to find ways to be able to continue everyday life in the best possible way with a minimum of pain. All participants had found solutions or tools to extend their spectrum of action. These solutions were divided into six different categories; *having a variety of treatments; adjusting ways to move; changing jobs; achieving social support; and using different aids.* These solutions were developed and tested over the years and used separately or in combinations.

**Having a variety of treatments.** All women revealed trying all sorts of therapies and treatments in their search of for pain relief. Over time, they had learnt what had effect and what did not. All participants often used one or more of the treatments in combinations to maximise the effect of pain relief.

*My exercise is like a routine, I can experience a lot of pain when I start, but I know exercising makes me feel better afterwards. Sometimes I have to take painkillers to be able to exercise. (Participant 3)*

The therapies/treatments mentioned and the number of participants that used them or had tried them are depicted in [Figure 2](#). All treatments were described as being effective to some degree. Pain medication reported were NSAIDs, paracetamol, codeine, and tramadol.

**Adjusting ways to move.** This category refers to how all participants had created innovative ways of undertaking practical things at home or at work. It could be a matter of keeping a good posture or avoiding unnecessary bending of the back as to minimize the number of repetitive movements. In other words, the participants always aimed to be self-sufficient and not allowing the pain impede performance.



**Figure 2.** Therapies/treatments mentioned in the interviews, and the number of participants that use them. Each participant used several types of therapies/treatments.

*You make up a strategy, mine is that I stand on my knees when I vacuum. And when I am emptying the dishwasher or the laundry machine, I lift everything up on the counter before I start hanging the laundry or putting away the dishes. I do this to avoid painful forward bending. (Participant 10)*

**Changing jobs.** All participants but one, were gainfully employed at the time of the interview and had changed both workplace and work tasks since the onset of their symptoms. Everyone said that the pain condition was partly or the sole reason of finding a new job. They also expressed worries that the pain would affect their ability to work or their employability in the future.

*I felt really bad and I thought my [work] career was over because of this, I thought I had completed my long education all in vain. I had to force my redeployment case, as to save myself a little. (Participant 5)*

**Achieving social support.** Most participants stressed the importance of receiving help and empathy from their next-of-kin. The support could be practical issues like receiving help from a family member or neighbours with house maintenance, gardening or more subtle support like not being questioned when needing to rest or not participating in activities due to pain, or other symptoms. Also, supportive colleagues at work were mentioned as important to be able to work. Other supportive actions included being cared for and not “forgotten” in social events they wished to partake in but could not always attend. However, to access social support from close relatives and friends, some degree of openness regarding the conditions was necessary.

*I've informed about my problems at work. And I always let them know if I slept poorly or have taken lots of painkillers since they can make me feel almost hung-over. It feels good that they know about my reasons for being ineffective. (Participant 2)*

Nevertheless, a few preferred to conceal their condition, as they wanted to be treated as anyone else. Thus, they did not inform co-workers or friends, even though they realized that their condition could be known to some degree.

*I don't talk about my pain with my friends, I guess they know that I have problems since you can tell sometimes, however, they don't treat me differently. I haven't said that I need some special treatment and I don't. I am like everybody else, but with back pain. (Participant 10)*

**Using different aids.** Participants used a variety of aids to alleviate pain and facilitate activities, that is, SIJ-support belts, medical corsets, pillows (or substitutes for them), adjustable beds, transcutaneous electrical nerve stimulation (TENS), acupressure mats, comfortable shoes, and clothes. One participant had a walking table at home to stand with support instead of sitting. However, participants also revealed narratives about humiliation and shame which made them choose less-visible aids.

*I often wear a thick down jacket that I can take off and use as a pillow in order to sit more comfortably. Usually, I do not bring a real pillow, this is nothing that you show off in public. (Participant 7)*

*My friends wear pretty shoes when we go on holidays, I wear jogging shoes. That is not so fun, but at least I can walk with them a while longer. (Participant 12)*

## Discussion

The scope of this study was women's descriptions of symptoms experienced through PPLP as well as their strategies to cope with the condition. The findings of this mixed-method study is unique since questionnaire data were available for at least three of four

time points over a 12-year period together with interviews of a selected sample of women from the cohort who all reported PPLP 12 years postpartum. Findings showed that living with PPLP had a far greater impact on women's lives than previously described. Participants revealed how they constantly assessed activities that caused or potentially could cause increased symptomatology, and a perpetual struggle to find strategies to be able to participate in everyday life.

Pain that persists longer than normal healing time, commonly three to six months, is defined as chronic pain [20], thus all participants in this study suffered from an evident chronic pain condition. Widespread pain has been shown to be common in women with chronic regional back or neck pain [21]. In addition, there is an increased risk for developing chronic widespread pain in women with chronic regional back pain [22]. In this study, we have been able to demonstrate that this is also congruent for women with PPLP 12 years postpartum. Other symptoms mentioned were mood-related as well as tiredness and sleep-disruptions. Depression as well as impaired sleep are well acknowledged to be associated with chronic LBP (CLBP) where both a depressive state and poor sleep predict higher pain ratings as well as pain increases the risk of sleep disturbances [23–25]. In addition, depression and impaired sleep are negative prognostic factors in CLBP [23–25].

Lack of cognitive comprehension of a condition has been shown to negatively impact self-management of pain [26,27]. Patients with chronic pain and poor understanding about their diagnosis have more pain catastrophizing, emotional distress, and illness worry compared to patients with a better understanding of their pain condition [28]. In this study, the participants had many different explanations to their symptoms. They also expressed fear of increased symptoms as a reason to avoid activity. This is in line with the much-used fear-avoidance model of developing chronic pain, that states that pain-related fear and avoidance as a safety seeking behaviour can lead to increased disability through physical degeneration and social isolation [24,29,30]. Congruent with previous research, some ways of understanding chronic pregnancy-related PGP are apparently adequate and helpful in regard to coping [14]. However, explanations can also render maladaptive coping, for an instance, self-blame can impair adaptive adjustment to chronic pain [31] as well as diminish the tendency to seek medical care [32]. In this study, we were able to demonstrate that some of the participants were convinced that the condition was self-inflicted at least to some degree. Nevertheless, the participants were not comfortable with the thought of a psychological component to their symptoms. Rejecting the impact of psychological components in CLBP might negatively affect the possibility to use psychological treatments or antidepressants as part of a multidisciplinary approach in managing chronic pain [33–36]. Obtaining self-efficacy is positive in regard to coping with chronic pain [37]. Finding good solutions to manage the pain was revealed to be an important feature in our participants' lives, making it possible for them to work and function in everyday life. However, all solutions were not objectively effective especially when seen in the light of their pain intensity and duration, as well as the long process in trying to find effective solutions. The lack of causal explanation of PGP [1] may have contributed to the long process of finding effective treatment alternatives. The diversity in treatment modalities used and tried, as well as the frequent use of complementary medicine and alternative medicine (CAM) [38] was noteworthy in the interview sample. Extensive use of CAM in LBP sufferers is described in earlier research [39], and this may suggest that effective treatment is not available in

conventional medicine [40] and/or reflect a lack of acknowledgement of the condition by conventional healthcare professionals [12,13].

Openness towards others regarding the pain condition with the intent to achieve social support was important to some of the participants while others wished to hide their condition. Pain-related social support as well as what kind of support desired and received are shown to impact the disability level of patients with chronic pain, whereas fulfilled solicitous support correlates with increased disability [41]. Taking on the role of being a “pain-patient” may be a risk in a social setting and enhance the development of chronic pain [24]. Shame and fear of showing off the pain and its consequences in public have earlier been identified in research [22]. However, hiding symptoms of pain comes with a fear of being discredited [42] and was consistent with findings in this study. Additionally, pain conditions may affect the ability to be gainfully employed. Earlier research has shown that chronic pain conditions often make it necessary to change tasks at work or work place entirely [39], and all of our participants had changed jobs, fully or partly due to symptoms of their PPLP. The possibility and ability to have a job that can be performed despite a chronic pain condition can have a positive impact on coping with the condition [43].

Narratives on planning ahead highlighted how the PPLP caused major cognitive occupation and planning to avoid any imaginative adverse scenarios that could cause more pain. Such strategies can be interpreted as fear of pain and/or pain catastrophizing. These are thoughts and behaviours that can be more disabling than the pain itself [38,44]. Nevertheless, there exists a concept that pain has an interruptive function which demands attention, in which chronic pain is viewed as a chronic interruption, increases the likelihood that the fear of pain itself becomes disruptive [45].

### Methodological considerations

There are some limitations to this study that need to be discussed. No physical examination of the participants was performed making it impossible to guarantee that all the participants suffered from PGP, hence the term PPLP has been used. Only one participant expressed symptoms that were more consistent with non-specific LBP rather than PGP. Despite the exclusion criteria that was used, one of the participants revealed additional morbidities or traumas to her pelvis and/or low back region during the interview. Nevertheless, her descriptions of the LP were in line with the other participants’ descriptions and thus included with the rest of the material.

The quantitative data demonstrated that the participants had higher pain levels and a higher frequency of sciatica than was expected based on the inclusion criteria. Examined variables were chosen to evaluate the selection of the interview sample in general but also specifically; examining possible differences between the groups for risk factors we earlier have demonstrated for chronic pregnancy-related LBP and PGP [6,9], as well as variables indicative of chronic pain [6,21]. The group of participants was small ( $n = 12$ ) which may imply few significant differences between the participants and the other respondents of Q4 apart from pain. A strength to this study was the mixed methods approach where the purposive sampling of participants for the interviews was performed among the responders to Q4 to gather deepened and specific information associated with living with persistent symptoms from PPLP.

Baseline data were available for all participants and questions posed in Q1–Q4 were similar to enable comparisons over time, as we have presented earlier [6]. All interviews were performed by two of the authors (CB and MP) and a topic guide was used to aid the interviews, but probing questions and participant’s ability to add momentous subjects to the interviews ensured vivid and rich narratives. To ensure credibility and thereby trustworthiness, the emerging findings throughout the steps of analysis were discussed repeatedly throughout the analysis among the first, second and fourth author and the final findings were assessed by all authors. The various authors’ professions and extensive clinical experiences of PPGP among authors further strengthened the objectivity of the analysis (KVA medical student, CB registered chiropractor, IM obstetrician, and MP registered midwife). The qualitative findings reflect the experiences made by the participants, and therefore may not be generalised. However, our results were in line with other qualitative studies involving patients with PPLP, especially in regard to the considerable impact on everyday life and the patients’ struggle to function [12–14]. Still, some unavoidable overlapping between a few subcategories might be questioned. The subcategory *Changing jobs* was a major part of the narratives regarding coping. Therefore, it needed to be presented as its own subcategory even though containing and relating to some elements from the subcategories *Achieving social support* and *Adjusting ways to move*.

### Conclusion

We have been able to demonstrate that PPLP caused limitations to most parts of life and to a far greater extent than previously known. Living with PPLP connotes constantly assessing activities that caused or potentially could cause increased symptomatology and appeared to be a continuous struggle to find strategies to enable participation in everyday life. Early interventions for women with PPLP with focus on effective treatment, coping strategies and individualized physical activities are needed. Future studies need to investigate possible pathoanatomical mechanisms and/or underlying causes pertaining to persistency of symptoms and non-recovery in order to reduce self-blame, and individual suffering, as well as societal costs.

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No potential conflict of interest was reported by the author(s).

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