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How life events are perceived to link to bodily distress: A qualitative study of women with chronic pelvic pain

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ABSTRACT

Chronic pelvic pain (CPP) is highly prevalent among women and the condition is poorly understood. In addition to multiple symptoms from the pelvis, CPP patients frequently suffer bodily distress like musculoskeletal pain and negative emotional, behavioral, and sexual implications. This paper is based on a qualitative study including semi-structured interviews with eight women with CPP. Our project has been conducted within the framework of phenomenology, particularly shaped by the concept of embodiment. We discuss the link between the lived body and CPP and address the value of making the life experiences of the patient relevant to understand this complex condition.

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Chronic pelvic pain (CPP) is a highly prevalent condition among women worldwide (Ahangari, 2014; Ayorinde et al., 2015) and studies in the field describe the condition through multiple and complex symptoms (Ayorinde et al., 2015; Lamvu et al., 2021) as well as repeated reports of challenging life experiences such as sexual abuse and difficult childhoods (As-Sanie et al., 2014; Lampe et al., 2003). The complexity of CPP is poorly understood. Explanatory models reflect an assumed complex causality, and the question remains how we can understand and best help women with this multifaceted condition. We performed a qualitative interview study with eight women with CPP. In this article we present findings on how our participants perceived their complex symptoms in relation to their life experiences. Even though our study is performed with a small sample of Norwegian women, their CPP and their accounts of stressful life events

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may be transferable to women in similar situations, and results may be relevant to treatment and work done elsewhere.

According to the definition, CPP includes both mental and physical symptoms with persistent pain related to the pelvis as well as functional problems connected to the various organ systems in the pelvis, with symptoms suggestive of lower urinary tract, sexual, bowel, pelvic floor, or gynecological dysfunction (D. Engeler (Chair) et al., March 2021). Both review studies and guidelines point out that research and treatment is challenging because of lack of consensus of classification of CPP among researchers and specialists (Ahangari, 2014; D. Engeler (Chair) et al., March 2021). Some specialists subdivide by anatomy, using diagnosis like vulval pain or bladder pain syndrome according to where the pain is felt. Others prefer the overall term CPP, emphasizing the lack of proven pathology to account for the occurrence of pain (IASP, 2020). Additionally, pain is often vaguely perceived or is overlapping between organs in the pelvic area, which is especially complex in the female body. We will in this paper refer to literature and studies using both the term CPP and more specific diagnoses such as vulvodynia, vaginismus, vestibulodynia and anorectal pain.

The variety of symptoms and dysfunctions is generally explained by theories of hyper-sensitization of the nervous system, the co-occurrence of several disorders (categorized as syndromes or multimorbidity) or as the consequences of living with pain over time (Ayorinde et al., 2015; Bergeron et al., 2020; Lamvu et al., 2021). In her editorial in *Health care for Women International*, Coven (2022) points to the finding that women seeking help for their chronic illness feel ignored or misunderstood, or that their symptoms are misinterpreted (Covan, 2022). This is also a common finding in studies on CPP (Grace & MacBride-Stewart, 2007; Shallcross et al., 2018) partly explained by the above-mentioned complexity of the condition. There are discussions about the limitation of understanding complex chronic conditions within a dualistic frame of pathology (Eriksen et al., 2013) and there has been a call for a non-dualistic concept of embodiment in order to understand CPP (Grace, 2003; Grace & MacBride-Stewart, 2007). Our study is based on a phenomenological approach, especially drawing on the concept of embodiment.

Qualitative research contributions to the field of CPP mainly identify and characterize the impact of pain on women's lives, their comprehension of the pain, their seeking of help and their coping strategies (Mellado et al., 2019; Toye et al., 2014). However, some studies view women's experiences of CPP in light of the social construction of sexuality, womanhood and femininity (Grace & MacBride-Stewart, 2007; Groven et al., 2016; Shallcross et al., 2018). The latter perspectives are mostly found in the

field of sociology, anthropology and psychology. Guidelines and review studies largely recommend a multidisciplinary approach in both investigation and treatment for this complex patient group. Thus, research on CPP may be of interest for different medical professions as well as researchers and other professions within all the fields searching to understand the complexity of women's health.

Coven considers in her editorial (2022) that stress appears to be an underlying factor contributing to chronic illness in women. Studies show that CPP affects most aspects of the patient's life. However, we still know little about how women's lives affect the CPP, e.g., how their challenging life experiences influence their multiple and complex symptoms. Despite the increasing understanding of the complex impact life events have on physiology, with a particular focus on the connection between adverse life experiences and disease (Felitti et al., 2019; Tomasdottir et al., 2016), we do not find this focus to be present in previous research aiming to understand women's CPP. The research question we address in this paper is how the women in our study perceived their complex symptoms and bodily distress in relation to their life experiences.

Methodology

This study is framed in the theoretical perspectives of phenomenology, the concept of embodiment and the work of Merleau-Ponty. His claim that all experience is embodied (Merleau-Ponty, 2002) enables an approach to understand bodily experience through a philosophy that exceeds the dualism between body and mind. The insight into this concept frames the whole study in relation to the research question, the methodology and the analysis process. Our research is based on the assumption that people give meaning to their experiences through interpretative processes, and that they act intentionally in relation to their social environment.

Method

Recruitment

We recruited eight Norwegian women with CPP, who gave their consent to participate after receiving written and oral information about the study. The semi-structured interviews are part of a larger study on women's experiences after receiving Norwegian Psychomotor Physiotherapy (NPMP) as treatment for CPP. NPMP aims to improve function by increasing body awareness. In the approach, body posture, respiration and muscular tension are considered to be closely related to emotional states (Dragesund & Råheim, 2008). The participants were recruited via five specialists in NPMP

responding to a request addressed to the professional group for NPMP therapists in Norway. The request was to invite adult female patients with CPP to participate in an interview study combined with video recordings (the video material is not part of this study). The participants were recruited before starting NPMP and the interviews took place after approximately six months of treatment. We received approval of the study from the Regional Ethical Committee under the Norwegian Health Research Act in January 2019 (REK-Nord 2018/2533), and from the Norwegian Center for Research Data regarding personal data protection.

Participants

All the included women were from urban areas, six of them from the north of Norway, and the remaining two from central and southern Norway. Aged between 19 and 56, only two of them had children. Five of them were in a relationship, and all identified themselves as heterosexual except one. She declined to be referred to as a woman, but preferred the category of a-gender. Two of the women were students, two of them were working and the rest were on sick leave (two of them for more than one year). The women had overlapping symptoms from the pelvic area and only two of them had received a diagnosis from the pelvic area, respectively irritable bowel syndrome and endometriosis. Two of them had other diagnoses, namely epilepsy, psychogenic non-epileptic seizures and weakened immune system. They all suffered muscular pain from many parts of the body, and for some of them exhaustion, anxiety and depression were their main problems.

Research team and reflexivity

The first author is a PhD student and a physical therapist specialized in NPMP with extensive experience in treating women with CPP. The second and third authors are professors of medical anthropology and physiotherapy, respectively. Repeated discussions between the three authors helped to raise awareness of hidden aspects of preunderstandings related to the first author's clinical background. The research team's experiences from different disciplines helped to challenge the understanding of the material.

Data collection

The first author interviewed the participants individually between September 2019 and March 2020. Seven of the interviews took place in an outpatient clinic in a hospital. Due to the COVID-19 pandemic, the last interview took place on the Teams digital platform with the participant in her own home. All interviews lasted between 60 and 90 minutes and followed the

same semi-structured interview guide with questions about living with CPP, the NPMP treatment, experiences of their body and expectations for the future. The interviews were performed with open-ended questions, with the goal of making the participants feel as free as possible to speak about their lived experiences of the topic chosen (Brinkmann & Kvale, 2015). During the interview, they were asked to clarify anything that was unclear to the interviewer, and they would likewise ask the interviewer to clarify when they found it difficult to understand the questions (Lindseth & Norberg, 2004). This interaction in creating shared meaning helped the interviewer to keep an open mind. During the interviews the body language of the participants was now and then commented on by the interviewer and thus became a recurrent theme reflected upon by the participant. Notes taken during and after the interviews, on body language, tone of voice, emotional states and changes in energy, are also included as data. The interviews were recorded, and the first author transcribed half of the interviews verbatim, while a professional transcriber transcribed the remaining half. The text to be interpreted consisted of a detailed transcript of verbal and non-verbal communication. Non-verbal communication was marked in the text, such as [almost whispers], [weeps while talking]. The transcripts were repeatedly checked against the audio files to ensure that the text reflected the participant's stories as closely as possible and the first author added notes about non-verbal communication when this was not captured in the transcribed text.

Data analysis

The analysis started during the data collection with the first author's interpretations of the participants' spontaneous descriptions and reactions (Brinkmann & Kvale, 2015). The analysis process continued with interpretations of the text moving back and forth over the following five steps inspired by the phenomenological "discovery-oriented" approach of Giorgi (Giorgi, 1997; Giorgi, 1975) and Brinkmann and Kvale (2015). Step 1) All three authors listened to the interviews and read the transcripts in order to gain a sense of the material as a whole. Step 2) The first author then divided the entire material into meaning units. Each meaning unit was interpreted in a descriptive way to a condensed meaning close to the participant's meaning, as the researcher understood it. This coding process was done for each interview individually. Once this step was completed, all the data were gathered as meaning units and codes. The NVivo software program simplified the complex process of organizing the overall material to look for patterns. Step 3) The next step entailed considering the essence of the meaning units in line with the main purpose of the study, as an embodied comprehension of the participants' stories. In this

process, the first author structured the material into sensitive expressions that reflected the field of interest, carefully keeping in mind the context of the meaning units, thus considering each meaning unit as a part of the interview as a whole. The context included the first author's overall impression of the participant, and the specific non-verbal communication that arose during the verbal communication. While the meaning units were being condensed into descriptive themes, additional reviewing and refining of the themes were performed in order to reach agreement between the authors and determine which themes were essential and in which way for the phenomenon under study, and which were not. Repeated reflection and literature reading helped to illuminate various meanings in the raw data from which the essence was taken. The MindManager software program was a help to visualize connections between the themes and identify the patterns in the material. Step 4) Moving back and forth in this analysis process helped to synthesize the meaning units into a description of a final set of themes. Finally, the first author listened again to each interview with the NVivo and MindManager results to hand, to ensure agreement between the interviews and our findings. Step 5) The analysis continued in the writing process where all three authors continually evaluated and discussed the essence of each theme and their relationship.

Outline of results

We ended with the overall finding of three overarching themes relevant to the participants' stories about how their life experiences affected them physically and what this entailed. '*Life experiences stick to the body*' reveals how previous overwhelming events, traumas and current strains became a physical issue that affected the women's everyday life. '*Bodily responses of tension and pain*' link the women's everyday struggle to muscular tension and CPP. '*Keeping sensations at a distance*' gives insight into how the participants handled bodily distress and sensations by disconnecting from their bodies and their own needs. In the presentation of the results, we present quotations from the interviews to support the findings.

Life experiences stick to the body

All the participants talked about how trauma, grief and current strains have affected and still affect their body. Despite having great variety in life experiences, they expressed how overwhelming life events were connected to their extensive bodily distress, including CPP. Their stories of traumas referred to sexual abuse, painful investigations in the hospital and difficult childhoods. They revealed how the memory of the traumatic episodes engendered bodily reactions. It was as if past experiences never

left their bodies. Eva was raped when she was 16 years old. When she talked about this brutal experience, she got bodily responses evoked by the memory of the assault:

I find it hard to breathe and my chest gets tight [her voice breaks a little], it feels like my heart's in my throat (...), however much you talk about it. Like it never gets any easier [she has had an energy breakdown], I get stomach pains, I start to get queasy.

The participants' many stress symptoms such as breathing problems, heart palpitations, nausea and persistent muscular contraction were all perceived as reactions to their life experiences. Their problems in concentrating and their continuous tendency to fumble or clench their teeth were likewise understood as signs of stress and unease. For some this bodily distress was related to ongoing concerns such as a painful divorce, worries for the future, overwhelming worries for a child or chronic disease (epilepsy, PNES and weakened immune system) causing insecurity and fear. Repeatedly, the women pointed out how unpleasant memories, fears, stress and pain were perceived as located in the stomach. Susan described her stomach as a container of grief:

My feelings are in my stomach, it's really crazy (...) there's a lump there, it's completely full of something and it's big. Yes, like it really fills my whole stomach.

The participants revealed that most of the above mentioned bodily reactions were beyond their control, overruling their will and reason. The bodily memory of traumatic experiences could release severe reactions. One of the participants had since childhood been exposed to anal investigations in the hospital in the search for pathology causing her stomach pain. She described how these experiences generated panic despite trying to be rational about it:

Felicia: They held me down when they put in tubes, there's been a lot of that sort of abuse (...) I've sometimes tried to take tranquilisers, but then I panic completely when they come closer with the tube and stick it in, I just lose my temper and I've had 100 examinations like that where they stick a tube up my bum (...). So it's like, even though I can think rationally that now nobody means anything bad by it, it doesn't make any difference, because those feelings are still in my body.

This experience goes hand in hand with what the participants expressed as feeling "too much" all the time, as if their body had become vigilant and was overreacting. Eva kept mentioning how all sorts of resistance and negative information could cause anxiety attacks, and increase pain and exhaustion:

(...) but if I had a huge amount of stress or was very depressed or, like, well, I had an attack at school once because my best friend got very annoyed and shouted at me a bit because I was being unreasonable, and I was. And then I felt sad, because

then I imagined that we'd never be friends again, so then I had an attack. And then I stayed in bed for a week as well. I just couldn't go to school.

Emotional strain and trauma were largely described as the cause of disease and for some the direct cause of CPP. Ann linked her anxiety, restlessness and CPP to an episode of sexual assault:

I was abused before I was 16 (...). And people didn't believe me, then after about six months I started to feel terribly agitated inside, and I needed to go out for walks a lot, I started to have lots of nightmares and got very anxious. I got loads of symptoms but I didn't understand what they were. And then I gradually started to get stabbing pain in my pelvis. I suppose it was because I was so tense after what happened to me.

Generally the women talked about how the body reacts to life's many challenges and the fact that these reactions feel overwhelming and beyond their control, leaving them with the feeling of being too sensitive. Tension was a topic they kept coming back to when describing themselves and their habitual reactions.

Bodily responses of tension and pain

The women shared troubled feelings regarding the pelvic region of their body. They described their vulva and vagina as ruined, gross, and disturbing. Further, they revealed feeling a constant, uncontrolled tension in the pelvic floor muscles. Melanie described this tension as a closed gate that was too painful to go through:

(...) not quite in the opening, but just a bit further in there's a kind of barrier... A barrier that you have to get past, but it might be too painful to get past (...).

Some referred to tensions in the pelvic floor closing the entrance to the vulva as a protection from intrusion. Sexual abuse specifically led to the perception of the pubic area as a particularly vulnerable part of the body:

Eva: And what happens almost every time I have sex is that it gets so tight in there that the penis is pushed out and can't get back in (...) I've thought that this might be happening unconsciously because of the rape, like my brain suddenly sends signals that this is not okay!

Ann: I can't relax as far as my pelvis is concerned. Because I don't like anyone being down there... then I don't feel like I have control.

Increased muscular tension was perceived as a protective reaction and a response to or a warning of threats, which made intercourse, gynecological examinations and use of a tampon impossible, because of tightness and pain. They described dreading or avoiding intercourse because of

intense pain in the pelvic region during or after the sexual act. Regardless of the pain, they continued to have sex, or kept on trying to complete intercourse. Their explanation for this was to find out whether it was still painful or because of their partners' wish for sex. The participants described how they longed to be able to have intercourse and Felicia described a vicious circle where fear of pain decreased arousal, leading to more pain and body tension:

When I'm lying there and I've kind of got so stressed, well, I don't feel like it, I feel kind of inadequate (...) I get embarrassed and ashamed and really just want to get out of the situation as soon as I can (...) if it hurts and I just stop, it will be worse the next time I try, because then my body remembers it so then I automatically get like that, I kind of hold off and get tense. And then it will definitely hurt.

Not being able to have pain-free sex left them with feelings of shame for not being good enough. Notably, Melanie had not told anyone of her failure to have intercourse, and she indicated how normative expectations about being sexually active influenced this decision:

I haven't told anyone about this, only healthcare staff and my husband know, so I suppose it's really embarrassing that I can't do it, or that I feel I'm not good enough. You're supposed to have an active sex life, I haven't even told my closest friends (...) I haven't told anyone... so that explains something about how it...

Pain preventing the women from having sex also led to worries about their future. If they could never have intercourse, how would they ever get a boyfriend, or have children. The thought of giving birth seemed frightening for some when it felt like something was wrong "down there". The women talked about multiple symptoms from the pelvic region, like frequent and painful urination, bladder infections, hemorrhoids, occasional painful defecation and a feeling of incomplete emptying of the bowel. On the one hand, the tension in the pelvic floor muscles prevented entering the vagina, while on the other, the women talked about how tension obstructed natural functions such as emptying the bladder and bowels:

Ann: When you feel you need to pee a lot, so you sit there and well, now it's got to come somehow. And so I sat for a bit, I managed to pee in the end, but it takes a while before the muscle kind of relaxes so I can pee.

In addition, the women described the tension in the pelvic floor as connected to tension in other parts of the body, and they reported tensing up in situations when they felt vulnerable. Their vulnerability was evident during the interviews in their ways of expressing themselves, through their body language, tone of voice, stumbling over words, constant repetition and whispering when something became difficult to talk about, or reluctance to discuss topics they referred to as difficult. One of the participants chose to keep her big winter coat on and they generally seemed tense.

Felicia: Yes, especially if I go into a new place, or meet someone, then when I sit down it's like my whole body automatically tightens up.

Being tensed was a recurrent topic and particularly distinct in the stomach and jaws, but also in the face, shoulders, neck, legs and feet, and they described being regularly short of breath. The participants were aware of a pattern of protection in their everyday body posture, like crossing their arms and legs, lifting their shoulders and contracting their stomach. Tania felt unsafe sitting on the toilet, and even on a chair, and described how she tried to protect herself by contracting her gluteal muscles and tilting her pelvis backwards:

I tighten my buttocks and sit down almost on my back (...) I'm afraid of getting something in there [the vagina] (...). It's always been like that. I almost completely clench my buttocks when I walk, and I don't really know why that happens (...). I often walk with my knees pointing inwards, I sort of don't feel I can open up.

What seemed to be a common feature of experiences of intrusion of the vagina, routine practices such as toilet visits, and situations of being vulnerable in general was a recognition of how the body responds to situations and settings with muscular tension. Feelings like fear, stress, worries, grief and anger were common triggers of tension. Eva drew a direct link between painful feelings, muscular tension and pain:

I know when I talk about things that have happened to me before, or I hear some sad news, it triggers something in my body that makes my muscles tighten up, and this is connected, so I can almost be sure that if I hear someone's dying, or I hear that someone's fallen ill, or if anything's happened, then I can almost expect it will hurt because it's completely natural in connection with the muscles around the pelvic area.

Overall, the participants experienced their muscular tension and their symptoms as ambiguous. Tensing the muscles was understood as a way of reacting to life events, and simultaneously the cause of the painful symptoms in the pelvic area.

Keeping the sensations at a distance

The participants described how they consciously and unconsciously tried to avoid sensations of distress and discomfort. Actions like working hard and being physically active were described as a 'refuge' to keep restlessness and stress at a distance. They could escape painful thoughts, feelings and sensations by watching television series or keeping themselves busy. Painful feelings were connected to the lack of understanding of their pelvic pain in the health care system or their shame at being unable to have sex. They explained that they 'locked out' the sensation of aching

muscles or painful body parts, but mainly the sensations they sought to avoid were related to a troubled past and ongoing worries for the future. Despite differences in life experiences and daily concerns, they shared the feelings of otherness, guilt, shame, loss of control, grief and anger. Tania tried to suppress the painful feelings related to having a child with special needs:

I do know that I ought to face up to it soon and be able to talk about it (...) I want to [accept it], but at the same time I don't want to, because then I feel it's my fault that it's got like that (...) now it hurts so much (...) so I almost feel like going (...) distancing myself from it [she cries and sniffs and crouches down when she talks about this].

Tania expressed how the subject created overwhelming feelings, making her tense up, avoid meeting the interviewer's gaze and want to leave the interview, all to keep the sensations at a distance. The women revealed feeling detached from the pelvic region of their body and described feeling numb and having decreased sensations of parts or the whole of their body. Some even experienced losing contact with their body:

Maria: Sometimes, I can sort of feel like my legs are not there. If I lie still for a few minutes and then feel, I don't know how I've put my legs without looking at them or touching them, so then they might be to the right or the left and I don't quite know how, if I can't see them. Because I kind of can't feel them (...) Yes, and my arms too.

This lack of contact was not entirely negative. Losing the feeling of themselves was described as a protective behavior to avoid the overwhelming bodily sensations they felt unable to deal with. Ann described how she could leave her body completely:

It's a big problem for me that I'm almost dissociated from the situation. Many times I've sort of felt like I'm disappearing from my own body and then I can almost look down on myself. I sort of disappear completely. When I don't have complete control, I disappear (...). I think it's because of the abuse, that's what I think. As soon as things feel nasty, well, then it just, I just disappear like that, protecting myself.

Some referred to sudden memories of past traumas triggered by smells, sounds, words or 'almost anything', taking them back to a painful memory they wanted to avoid. The participants explained their general tendency to distance themselves from their own body, becoming numb and even leaving their body completely, as a way to escape from the discomfort they felt both in the memories of previous experiences and in their daily ongoing challenges. The participants shared many examples of how bodily distress prevented them from living the way they wanted. Anxiety, depression, exhaustion, weak immune system and pain prevented them from

working, taking an education, having a partner and getting pregnant. Thus, they perceived their body to be an obstacle to a normal life. At the same time, they understood their symptoms to be signs from their body telling them about their needs. They gave examples of exhaustion, anxiety, pain and muscular tension as ways their body communicated needs and they shared examples of pushing themselves even though signals from their body warned them not to:

Eva: (...) I usually force myself to do it [laughs a little], and that's not good, because then I'm doing myself a lot of harm, and then I can almost stay in bed for several days (...) my whole body can ache because of that (...) But I think it's because my body's saying no! Now you have to relax.

Notably they referred to the same symptoms as not only a way for their body to set a limit but also an obstacle to living the way they wanted to. Melanie said the pain during intercourse seemed to be an attempt to scare her from having sex, and she had to be careful not to conjure up too many negative memories, which would make the pain worse. When listening to their bodily signals made it more difficult to live the life they wanted to, they avoided listening to their body. This was yet another reason to keep the sensations from the body at a distance.

Discussion

Overall, the women in our study talked about how their bodies reacted to life's many challenges. They expressed vulnerability both during the interview (communicated both in words and non-verbally) and in their descriptions of how they reacted whenever they felt vulnerable. Furthermore, they referred to their bodies as troublesome by limiting their opportunities for socially expected lifestyles. The finding of being in conflict with one's body is a common theme in various bodily ills (Leder, 1990; Svenaeus, 2000), and is also found in studies on CPP (Kaler, 2006). We found that our participants alternated between talking about a double experience of their own body, both as a feeling 'subject' responding to life's challenges (as something they were) and as a troubled body 'object' (as something they had). In the philosophy of phenomenology, this 'double body' experience is one of the core issues in the concept of embodiment (Wehrle & Doyon, 2020), where our lived body is considered to be our access to all experience and simultaneously to be all we are (Merleau-Ponty, 2002). In light of this 'double body experience' we pursue our participants' descriptions of their body both as a physical thing, visible and touchable (vulnerable to abuse, damage and pathology), and as a sensing subject, functioning as the medium for their experiences where the vulnerability is felt in the center of their being.

'Life experiences stick to the body'

Our participants revealed how their bodies responded to stressful life challenges with multiple symptoms such as exhaustion, musculoskeletal pain, bladder and digestive problems, anxiety, depression and CPP. The findings of symptoms related to life experiences can be explained by a theory of how multiple powers affect the body as a whole. The interdisciplinary field of *psychoneuroendocrinoimmunology* considers the human organism as a structured and interconnected unity where the biological and psychological systems influence each other reciprocally (Bottaccioli & Bottaccioli, 2017). The model of 'allostatic load' (McEwen & Wingfield, 2003) has been used to explain how difficult life experiences may lead to stress and cause an overload of the body's capacity for adaption (Kirkengen, 2008; Tomasdottir et al., 2016). Human beings are open biological systems constantly interacting with the environment and stressful events will have a simultaneous impact on the nervous system, the endocrine and hormone system, the musculoskeletal system and the immune system (Kirkengen, 2008). Excessive strain on any of these systems can cause symptoms all over the body (Kirkengen, 2008). The association with adverse experiences like childhood maltreatment and sexual abuse has been shown in previous research (As-Sanie et al., 2014; Bergeron et al., 2020; Lampe et al., 2003). Although some studies caution against suggesting simplistic explanations such as that CPP may be caused by sexual abuse (Bergeron et al., 2020), our participants were in no doubt about how these experiences affected their body. This finds support in a study by Hilden et al., who refer to a stress-illness theory to explain how sexual abuse can cause ill health based on emotional responses and suppression of the immune system due to stress (2004). Furthermore, Hilden et al. (2004) point to the finding that several diagnoses are more frequently found among sexually abused patients. The diagnoses they mention are often referred to as 'vague and diffuse' and most of them match the symptoms reported by the women in our study, such as CPP, irritable bowel syndrome, fibromyalgia, sexual dysfunction, dysmenorrhea, abdominal pain, chronic fatigue and depression. Considered in terms of the 'overload' model, the complexity of symptoms in our participants may be understood as systemic reactions to stress. To understand their symptoms in the pelvis in particular, we find confirmation in the literature that points to the impact of overload of the neuro-hormonal and musculoskeletal systems. In the emotional states of restlessness, stress, anxiety and depression, as described by our participants, the altered neuro-hormonal reactivity may affect internal organs such as the bladder and intestines, as well as connective tissue and sexual organs (Bergeron et al., 2020; Spoelstra et al., 2019). Stress also affects the ability to return to a state of rest and equilibrium (Heim et al., 1998; Van Der

Kolk, 1994) which may increase the overload. Furthermore, muscular tension is a well-documented stress response which was a recurrent finding in our study. Tension in the pelvic floor is the prevailing theory for explaining pain during penetration as well as functional problems and pain on emptying the bowels and bladder (Messelink et al., 2005; Prendergast & Weiss, 2003).

'Bodily responses of tension and pain'

We found that troubled life events were the central issue for the women in our study. Throughout history, women with pelvic pain with no pathology to explain it were often considered to suffer from 'hysteria', indicating that their pain was a sign of psychological instability (Grace & MacBride-Stewart, 2007). Our participants revealed their unstable state as natural responses to overwhelming life events and in summing up their description of their own bodily responses, they reported feeling constantly on alert. In addition to reactions like stress, anxiety, depression and pain, muscular tension was frequently mentioned. They had muscular tension all over their body and saw their uncontrolled tension in the pelvic floor muscles as a part of a larger pattern of tension. They related both their muscular tension and their feeling of dislike of the pelvic region to their CPP condition. However, these reactions were mostly mentioned in connection with a sense of vulnerability and loss of control associated with sexual abuse and fear of penetration. Research on women with CPP frequently reveals a finding of tension in the pelvic floor muscles (Bergeron et al., 2020; Reissing et al., 2005; Spoelstra et al., 2019). The notion of contraction of these muscles as an emotional response has been investigated in experimental studies where the contractions are identified as protection to penetration of the vagina, mainly explained as a learned response following painful penetration or perceived danger (van der Velde & Everaerd, 2001). In other studies, consistent with this focus, tension in the pelvic floor muscles and problems in relating to the pelvic region are regarded as connected to pain in this area (Haugstad et al., 2006; Kaler, 2006). Additionally, the frequently reported forms of mental distress in women with CPP, such as anxiety, depression, low self-worth, self-blame, guilt and shame, are likewise understood as secondary to their CPP (Mellado et al., 2019; Sadownik et al., 2012). Some studies show how social constructions and narratives on sexuality and gender contribute to feelings of shame, low mood and anxiety, due to the women's inability to fulfill expected norms and enjoy normal sex (Groven et al., 2016; Marriott & Thompson, 2008; Shallcross et al., 2018). The common finding that women continue to have sex despite pain has been shown to be grounded in the feeling

of failure to be a normal woman (Elmerstig et al., 2008; Marriott & Thompson, 2008), which has also been linked to social isolation and depression (Marriott & Thompson, 2008). Thus, these studies identify the reason for the women's emotional strain to go beyond the actual pain experience, even though pain is still the main cause of their extensive suffering. Our analysis supports the findings of distress due to sexuality-related problems caused by CPP, such as the fear of not being able to get a partner or become pregnant. The women in our study also felt ashamed because of their failure to have a normal sex life and they continued to have sex despite pain and their lack of sexual desire. However, our participants mainly related their multifaceted distress to aspects of the broader context of their lives. They explained that they tensed up because of the general threat of living rather than the more specific threat of pelvic pain. Among their descriptions of overwhelming emotions, the feeling of shame is a distinct finding in our material. In addition to our participants' accounts of feeling different, deficient and vulnerable and hating oneself, we find that the physical manifestations of our participants can overall be described as expressions of shame. During the interviews they expressed feelings by averted gaze, downward head movements, slumped posture, fumbling, unusually low- or high-pitched voice, sweating, stammering and dryness of mouth. They talked about dazed sensations, tenseness of muscles and constriction of the diaphragm. In the literature, we find these to be physical manifestations of shame (Dolezal, 2015; Goffman, 2005; Zahavi, 2020). Shame is a particularly prevalent emotional strain found in the literature on CPP (Groven et al., 2016; Marriott & Thompson, 2008; Shallcross et al., 2018); however, the reason for our participants' feelings of shame to some extent diverges from the focus in previous literature where pain is the basis for comprehending the complexity of these women's suffering. The expressions of shame of our participants were mainly mentioned in relation to accounts of not coping in life because of other challenges than pain. They largely blamed their failure to study or find a job on exhaustion, anxiety and concentration problems.

Keeping the sensations at a distance

Our participants described a desire to move away when the emotions that unfold in their body became too painful to relate to. They gave various examples of inescapable, overwhelming events that made them want to flee and described feeling disconnected from their body using phrases such as 'being numb', 'not knowing where their body was', 'not feeling their own body' and 'leaving their body'. A disrupted way of relating to the pelvic area has also previously been shown in qualitative studies on

women with CPP (Danielsen et al., 2019; Kaler, 2006; Sadownik et al., 2012). In a quantitative study on women with CPP, Haugstad et al. point to their participants' 'decreased body sensations,' 'decreased body awareness,' and 'a pattern of somatic dissociation' (2006, p. 642). Even though these studies support our findings they relate the women's disrupted way of relating to bodily sensations to the onset of pain. Our participants only to a minor extent related this disconnection to bodily discomfort and pain, but instead to their overwhelming emotions. The phenomenon of detaching oneself in the case of sensory and emotional fragmentation of experience is described as dissociation (Van Der Kolk & Fisler, 1995). In the context of traumatic experiences, Van Der Kolk writes that it is a well-described reaction to 'space out' during the moment of a trauma and to continue to do so in everyday life when memories of the trauma occur (1995). Our participants' traumatic memories are regularly stirred up and they referred to how traumas 'stored' in their bodies suddenly and unpredictably could be awakened from sounds, smells and words in everyday life. The trauma they once faced was over, but the experience was stuck in their body. Literature in the field shows that recall of traumatic experiences is generally triggered by exposure to sensory or affective elements associated with the trauma (Kirkengen, 2008; Levine, 2010) and traumatic experiences are understood to be stored in the body as necessary knowledge of the world to ensure survival (Levine, 2010; Van Der Kolk, 1994). Here, one might say that the trauma is no longer in the past event, but in the nervous system (Levine, 2010). Even though not all of the women in our study referred to experiences of trauma, they all experienced some sort of distance, numbness or lack of contact with their own body. Through the concept of allostasis, McEwen and Wingfield (2003) suggest that social conflicts and dysfunction are challenges that do not necessarily trigger escape as a behavioral response:

Another type of reaction to a potentially stressful situation is an increased state of vigilance, enhanced by anxiety and worrying particularly when the threat is ill-defined or imaginary and when there is no clear alternative behavioral response that would end the threat (2003, p. 4).

In light of this statement we may consider the dissociative pattern of our participants as a response to ill-defined stressors or a lack of alternative reactions. Stress and threats were constant variables in our participants' lives and they felt trapped in life situations they were unable to change. Their dissociative reaction may be understood as the only possible way to escape painful sensations as they had no possibility to escape the situations causing the pain. Their stated aim of keeping their body at a distance supports the findings in other studies, explaining the separation of the body as a survival mechanism to protect the self from the painful

experience of negative emotions (Halvorsen et al., 2013; Kalman, 1999). Our participants' protective mechanisms of unintentionally and deliberately ignoring signals from their body made them go beyond their needs and push themselves beyond their limits. Interestingly, it has been pointed out that shame is a particularly unpleasant sensation: 'individuals go out of their way to avoid shame (...) even when this avoidance means harming or hurting the self' (Dolezal & Lyons, 2017, p. 258). Emotions are experienced through all kinds of bodily sensations as signals telling us how we feel in a given situation. One consequence of keeping the body at a distance is to lose track of one's emotions and thus the possibility to pursue one's needs. When our participants distanced themselves from their bodily sensations, we may suspect that they lost sufficient information about their own feelings to self-regulate behavior and bodily processes altogether. Such an assumption may shed light on their experiences of overreacting and being too sensitive.

Methodological considerations

We have striven to provide trustworthiness and transparency in this study through a detailed presentation of the results illustrated with extensive quotes enabling the first-person perspective of the women in our study to be visible (Kvale et al., 2015). Transparency has been provided by the presentation of the author's professional background and the philosophical framework in which this study has been conducted. A weakness in this article is the limited description of the physiotherapy treatment (NPMP) the participants had undergone. In NPMP part of the treatment is to explore how life leaves traces in the body and shapes the way people relate to the world. Our interpretation of our participants is based on this understanding. Additionally, the women had explored this connection in treatment. As the interviews were conducted after the treatment period, it is likely that the participants' reflections were influenced by experiences gained in treatment, especially since part of the interview dealt with their experiences with NPMP. However, we have not elaborated on the role of NPMP in women's experiences of their bodies in the present article, in view of the fact that NPMP treatment for CPP will be the topic of our next article.

Concluding remarks and clinical implications

The present study allows for a non-dualistic comprehension of our participants' stories and our analysis demonstrates how the women in our study referred to most of their physical problems as secondary to stressful life events. They narrated their embodied experiences with accounts of how their bodies acted and reacted in accordance with lived experiences.

In summing up, the women in our study described several protective responses connected to the experiences of their vulnerable ‘body subject’. These protective responses were the result of pain and widespread distress perceived in a troubled ‘body object’. Taken together this implies that our participants included their subjectively experienced body in the understanding of their extensive bodily distress. How health care providers and others working with women’s health view the body is crucial for the understanding of any disease and shapes any assessments of patients. If we embrace our participants’ understanding and consider the subjective body to be relevant to CPP, the cause of pain may not only be sought in vulnerable patients’ physical body but also in the context of their lives. We encourage further research on CPP with an embodied approach to expand the understanding of this multifaceted condition by including subjective and context-sensitive considerations.

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