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Moving toward or away from sexuality

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1 INTRODUCTION

In this chapter, the topic and background of the study will be presented, along with the research question with a clarification of areas of focus, the purpose and relevance of the study, as well as an introduction to the topic of research.

1.1 TOPIC

The topic of this study is the relationship to sexuality among women with provoked vestibulodynia (PVD). PVD is a gynaecological pain disorder where pain in the vaginal opening is provoked by touch which directly affects the sexuality of affected women. The theoretical framework of the study is presented in chapter 2.0. The study is grounded in empirical data from qualitative research interviews with nine women who suffer from PVD.

1.2 BACKGROUND FOR THE CHOSEN TOPIC

I am a physiotherapist, with special training in Norwegian Psychomotor Physiotherapy and Pelvic Floor Physiotherapy (PFPT). The majority of patients I treat in my clinical practice suffer from provoked vestibulodynia (PVD). PVD is known to directly and negatively impact the sexuality of these women and their intimate relationships (Bergeron, Khalifé, Dupuis & McDuff, 2016, p. 259-260). My impression is also that the way these women relate to sexuality and how they cope with challenges in partner intimacy in turn impacts their pain experience and coping with PVD. This inspired me to conduct this study. I believe that gaining a better understanding of women's relationship to sexuality is essential to develop better treatment approaches that are tailored to each woman's complex reality.

PVD affects 12-20% of women of reproductive age and is the most common cause of dyspareunia (painful intercourse) among women in the West (Sadownik, Seal & Brotto, 2012, p. 22). Although PVD presents a serious health problem, there is a need for more knowledge to understand its aetiology and improve treatment (Desrochers, Bergeron, & Khalife, 2010, p. 106-107). In PVD, pain at the vaginal opening is provoked by touch, as when inserting a tampon, finger or attempting intercourse (Desrochers et al., 2010, p. 106; Goldfinger, Pukall, Gentilcore-Saulnier, McLean & Chamberlain, 2009, p. 1955; Pukall & Cahill, 2014, p. 12). Psychological factors such as anxiety, depression and fear avoidant behaviour are common in this patient group, which have been found to cause the pain to become chronic (Thomtén & Linton, 2013, p. 252; Desrochers et al., 2010, p. 106-107).

My hope is that this study can capture and present some elements of these women's reality that deserves more attention from health care personnel and that it may contribute to the development of better health care services for this patient group. I am also curious to see whether the study can contribute to forming a better aetiological understanding of PVD.

1.3 RESEARCH QUESTION

What do women who live with PVD tell about their relationship to sexuality?

1.3.1 NARROWING DOWN THE RESEARCH QUESTION

To guide the focus during the research process, the following two research questions were added:

1. How has their view and experience of sexuality come to be?

2. What are they attempting to achieve through their sexuality and what are their experiences of doing that?

1.3.2 DEFINITIONS

"Relationship" in the context of this research question reflects the acknowledgement that there is a relationship between the woman's *self* and sexuality.

"Sexuality" refers both to the sociocultural concept of sexuality as well as personal expectations, feelings and experiences. These concepts will be explained in greater detail in part 2.

1.4 PURPOSE OF THE STUDY

Although PVD has a direct, negative impact on sexuality, and several studies indicate connections between pain persistence and sexual problems in this group, limited qualitative research exists to date in this area. The purpose of this study is to meet the need for better help and support for women with PVD by contributing more knowledge about their thoughts and lived experiences of sexuality to health care personnel. The current study also seeks to provide a better understanding of how their relationship with sexuality has come to be, about what their concerns and struggles are, as well as any resources and victories in the area sexuality that may be of relevance to their coping with PVD.

1.5 RELEVANCE OF THE STUDY

As mentioned, PVD is a highly prevalent disease and the most common cause of dyspareunia in the West. It deserves attention for this reason alone. Studies of PVD are relevant in a psychological health perspective because anxiety, depression, fear avoidant behaviour and other psychological and psychosocial factors play an integral part in the development and maintenance of the pain (Thomtén & Linton, 2013, pp. 251-252; Desrochers et. al., 2010, p. 106-107). Research in this area does indicates that concerns and beliefs about sex and sexuality are enmeshed into these psychosocial factors (Krapf & Goldstein, 2016, pp. 288-289; Desrochers et al., 2010, p. 106-108). For example, Desrochers et.al. (2010, p. 107) found in their quantitative study that higher state anxiety, fear of pain and lower pain self-efficacy explained 22% of the variation in women's sexual impairment. More qualitative research is needed to understand these pain-exacerbating psychological factors and their potential role in the aetiology of PVD (Desrochers et al., 2010, p. 114). The present study may bring to light relevant information in this regard.

Authors Krapf & Goldstein (2016) emphasize the importance of the clinician's ability to facilitate open conversations about these topics through openness, comfort, trust and confidence (Krapf & Goldstein, 2016). However, sexuality is a topic of great stigma and taboo and often a hard one to broach both for the patient and the medical doctor or therapist due to feelings of embarrassment, shame, guilt etc., and limitations of time and experience on the part of the clinician (Almås & Benestad, 2017, p. 15; Fougner and Haugstad, 2015, p. 323; Krapf & Goldstein, 2016, p. 287-288). The diagnosis is often difficult to evaluate and treat (Krapf & Goldstein, 2016), and it is common that patients visit several medical doctors before they are properly diagnosed and referred to a skilled therapist for treatment (Ibid). Given the relatively high prevalence of PVD, it is necessary that health care professionals across different disciplines gain a better understanding of how sexuality can be experienced for women in this group so as to feel more confident and able to help their patients overcome the shame associated with talking about their sex-related pain.

The hope is that this qualitative study may contribute to alleviate these challenges by making these women's problems more easily recognizable in the eyes and ears of health care personnel. By presenting the lived experiences of a few women, I hope that general practitioners may be able to diagnose PVD more effectively and refer patients to appropriate treatment at an earlier time.

As knowledge about PVD spreads one can hope that a larger number of physiotherapists will choose to equip themselves with the necessary knowledge, skills and insight to treat this relatively large patient group. It seems wise to add to the existing theoretical knowledge base more qualitative research so as to give both patient and therapist better conditions, especially in dealing with the sensitive subject of sexuality, as it is of such importance to the evaluation of the patients' problems at the beginning of treatment, as well as recognizing progress over time and evaluate treatment outcome.

Studies that have looked at sexuality in relationship to the etiology of PVD have mainly focused on the prevalence of history of sexual abuse and rape. I find this problematic, as it seems to me that patients who have not experienced sexual abuse also struggle when it comes to self-acceptance, setting boundaries, and to discover, ask for and receive what they want without fear and shame in an intimate setting. Considering the limited knowledge of the etiology in PVD, it is surprising that qualitative studies remain few as they may bring new information to light (Malterud, 2017, pp. 33-35). It seems appropriate to add to the existing scientific literature on PVD more qualitative research that addresses sexuality specifically.

1.6 INTRODUCTION TO THE TOPIC

1.6.1 WHAT IS PROVOKED VESTIBULODYNIA?

PVD is defined as burning or stabbing pain in the vaginal entrance (vestibulum), provoked by touch and pressure lasting for 3 months or longer (Desrochers et al., 2010, p. 106; Goldfinger et al., 2009, p. 1955). Hypersensitivity to touch at the vaginal entrance is characteristic to PVD and a diagnostic criterion (Pukall & Cahill, 2014, p. 14). Although the majority of women continue to have sex, intercourse is unbearable for many (Groven et al., 2016, p. 823). PVD is the most common cause of dyspareunia among women of reproductive age (Goldfinger et al., 2009, p. 1956). Scientific studies on the prevalence of PVD differ somewhat according to variations of measurement, but most recent studies report a prevalence of between 12-20% of PVD among women of reproductive ages in western countries (Goldfinger et al., 2009, p. 1955-1956; Sadownik et al., 2012, p. 22).

1.6.2 UNKNOWN AETIOLOGY

There is no singular cause of PVD (Goldfinger et al., 2009, p. 1956). While there is agreement that the cause of PVD may be multifactorial, etiological knowledge is still lacking (Desrochers et al., 2010, p. 106-107). One theory is that PVD begins with a local infection, and that the pain becomes chronic as the result of increased sensitivity to touch (Backman, Widenbrant, Bohm-Starke & Dahlof, 2008, p. 379). Some researchers argue that a background of sexual abuse can precede the development of sexual pain later in life (Corsini-Munt, Bergeron, Rosen, Beaulieu & Steben,_2016, p. 316; Desrochers et al., 2010, p. 106). Psychosocial factors have been found to play an important role in the development and maintaining of pain (Goldfinger et al., 2009, p. 1956).

1.6.3 CHALLENGES IN SEXUALITY

Qualitative studies reveal that women with PVD feel pressured by social norms for what it means to be a woman and what the sex life within a romantic relationship should be like (Groven, Råheim, Håkonsen & Haugstad, 2016, p. 830). Women report feeling like intercourse is a duty, being torn between the desire to fulfil this duty and to protect themselves from pain (Ibid). Women with PVD have also been found to withdraw from body awareness (Craven, Thelen, Elliott & Lazear, 2016, pp. 530-535) and from intercourse (Braksmajer, 2018, pp. 424-430). The pain itself negatively impacts the sense of self in patient groups suffering from genital pain (Rosenbaum, Bernard & Wilhite, 2015, p. 551).

Women with PVD experience lower libido and arousal, with lower intercourse frequency in comparison to healthy women (Desrochers, Bergeron, Landry & Jodoin, 2008, p. 206). From their conversations with eight women suffering from PVD, Groven et al. (2016, pp. 827-833) found that women with PVD want to be able to have sex again. Other studies have found that doctors are often not capable of meeting the needs of their patients in terms of providing safe space for talking about sexuality and sex-related problems (Krapf & Goldstein, 2016, p. 288).

1.6.4 TREATMENT

Patients are most often diagnosed by a gynaecologist or dermatologist. A combination of physiotherapy, sexual therapy and cognitive behavioural therapy is recommended (Backman et al., 2008, p. 379).

1.6.5 ADDRESSING SEXUALITY IN TREATMENT

Researchers from multiple disciplines emphasize that physiotherapy treatment that targets increased tension of pelvic floor musculature should also address psychosocial aspects of healing (Bergeron et al., 2016, p. 267; Backman et al., 2008, p. 384). Considering this, sexuality should be a central topic for doctors and physiotherapists who treat these women. In Norway, Haugstad and colleagues have developed a treatment approach that combines classical physiotherapy interventions and cognitive psychotherapy called Somatocognitive physiotherapy which has been found to reduce pain in women with PVD (Fougner & Haugstad, 2015, p. 318).

1.7 THE HISTORY OF SCIENTIFIC RESEARCH ON PVD IN A NUTSHELL

In the beginning, research into the etiology of PVD was dominated by the separation of psyche and soma, seeing it as either a physical or psychological disease (Thomtén & Linton, 2013, p. 252). However, over the past 25 years there has been a growing consensus among researchers across multiple disciplines that a biopsychosocial approach should be applied to evaluation and treatment (Chisari & Chilcot, 2017, p. 88; Craven et al., 2016; Desrochers et al., 2010, p. 114; Thomtén & Linton, 2013, p. 252).

During the last decade there has been an increase in the attention toward sexuality among researchers from different disciplines, with a few qualitative studies addressing the lived experiences of women with PVD with direct focus on sexuality, as well as quantitative studies of psychosexual factors. A summary of these studies will be presented in part 2.0.

In the newly published ICD-11, PVD is classified as a pain disorder under the category of diseases of the genitourinary system (International Classification of Diseases (ICD), 2018).

2 THEORETICAL FOUNDATION

This section includes theoretical perspectives for the understanding of pain, the Self, sexuality and shame, as well as relevant scientific studies on the subject of PVD. I'm also including an introduction of Norwegian Psychomotor Physiotherapy, as it is relevant to understanding myself as a researcher.

2.1 PAIN

Pain is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (International Association for the Study of Pain (IASP), 2018, second paragraph).

2.1.1 PERSPECTIVES ON PAIN

For a long time, pain was understood as a physical phenomenon of biological origin (Butler & Moseley, 2013, p. 10). Advances in neurobiological research has shown that pain is a product of biological, psychological and social driving factors (Butler & Moseley, 2013, section 1).

From a biopsychosocial perspective, the function of pain is understood as the necessary unpleasant experience that alerts us to danger, or what our brain believes is dangerous (Ibid.). Phenomenologically, pain possesses "an utterly sovereign power, a sovereignty that marks the limit for my belief in my own power, my freedom and my determining right over everything in my life, over all its significance and meaning" (Vetlesen, 2009, p. 52).

2.1.2 PAIN IN THE CONTEXT OF PVD

Women with PVD describe their pain as burning, cutting, stinging (Groven et al., 2016, p. 819). Biologically, what leads to pain can come from processes that threaten the health of tissues, like an injury or inflammation (Butler & Moseley, 2013, p. 30). Signals from the tissues reach the brain where the actual pain experience is produced, the intensity being determined according to how dangerous the brain perceives the signal to be (Butler & Moseley, 2013, pp. 38-39). Psychological factors, such as what meaning attributed to the pain affect how pain signals are interpreted. Fear, catastrophizing and hypervigilance contribute to higher pain intensity (Ibid.).

Social factors, such as how others relate to one's pain affect the pain experience too. For example, in the case of PVD, both partner hostility and solicitousness (partner expressing concern) are related to reports of a more intense pain (Desrochers et al., 2010, p. 107). Psychosocial factors make the pain relational, in one way by virtue of being provoked by the penetration of the partner, in another because inability to have intercourse threatens belonging as one comes to see oneself as not a "real woman" (Groven et al., 2016, p. 820).

In terms of coping, it is relevant to mention the term *self-efficacy*. Pain self-efficacy refers to one's confidence regarding one's ability to function effectively while in pain (Bois, Bergeron, Rosen, McDuff & Grégoire, 2013, p. 2026).

2.1.2.1 SENSITIZATION

Over time (3 months or more), when pain becomes chronic as in the case of PVD, the processing of pain signals is altered in the nervous system. This process is called *sensitization* and can occur both in the local (vaginal) tissue (peripheral sensitization), and in the areas of the brain where the experience of pain is produced (central sensitization) (Butler & Moseley, 2013, pp. 82-83; Pukall & Cahill, 2014, p.14).

Psychosocial factors, which are highly prevalent among women with PVD, are integral to this alteration, specifically depression, fear (of pain), stress, catastrophizing and a tendency to misinterpret bodily sensations (Goldfinger et al., 2009, p. 1956; Pukall & Cahill, 2014, p. 17). Increased tension of the pelvic floor muscles may contribute to sensitization because of associated neurological changes in the tissue of the vaginal opening (Pukall & Cahill, 2014, p. 16). Psychosocially, this can be an effect of anticipating pain (Rosenbaum, Bernard & Wilhite, 2015, p. 552). Feeling pain when touch is applied in ways that would normally not elicit pain (allodynia) is a symptom of pain sensitization (Pukall & Cahill, 2014, p. 14). Hypersensitivity to touch at the vaginal opening is characteristic to PVD and a diagnostic criterion (Ibid).

2.2 THE SELF

As this study seeks to find information about the relationship it is implied that the Self is the other part of that relationship. From a sociological perspective, the development of the Self is a process of interaction with others (George Herbert Mead cited by Gretland, 2007, p. 40). Two aspects of the Self emerge during the first 3 years of our lives; a subjective "I" which takes action, reflects and refers to, and an objective "me" which reflects the expectations of others. The "me" makes it possible to take on the roles of others and to coexist according to general expectations of others by way of being able to take on their perspectives. According to Norwegian psychomotor physiotherapist Anne Gretland, the Self is experienced and expressed through the lived body by what we sense, feel, think, in the way we interact and carry ourselves (Gretland, 2007, p. 39).

2.3 SHAME

In line with the research question it seems appropriate to address the type of negative shame that can be experienced when one's sexuality is different from what is perceived as "normal" and socially acceptable. This type of shame leads to seeing oneself as not worthy of love and acceptance in the eyes of others (Farstad, 2016, pp. 25-28). A product of relationships, shame comes with the experience of not being seen by others and making judgements about oneself based on how one (thinks one) is seen by others (Ibid). Phenomenologically, shame is experienced as *being* wrong, with a desire to disappear as one wants to hide what's unacceptable and unlovable about oneself from the eyes of others (Ibid). Shame can be felt in the body as freezing, burning, numbing or physical weakness, as being constrained or bound (Ibid). A common concept in postmodern culture is that shame belongs to the past. In reality, modern shame concerns identity and self-image, whereas traditional shame had to do with family and traditions (Frønes, 2001, p. 70). This can make it particularly challenging for the person who feels shame, as feeling shame is shameful in itself (Wyller, 2001, p. 10).

2.4 SEXUALITY

For the purpose of this paper I choose the following definition by the WHO:

> "Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors." (WHO, 2006a)

2.4.1 PHENOMENOLOGICAL PERSPECTIVE ON SEXUALITY

According to phenomenologist philosopher Merleau-Ponty, sexuality and libido are the psychophysiological subject's inherent ability to form attachment with different environments, make decisions based in different experiences, and acquire behavioural structures (Merleau-Ponty, 1994, p. 118). A person's sexuality delineates his or her way of being in relationship to the world, i.e. in relationship to his or her (socio-cultural) time and in relationship to other human beings. In this way, sexuality gives shape to that person's history (Ibid.). According to Merleau-Ponty, desire and libido are dependent on the person being engaged and living in one's body in a way that allows tactile stimuli to be experienced in relationship to sexual relations, expectations and desires (Merleau-Ponty, 1994, p. 115).

While recognizing that sexuality is lived experience beyond those that involve our erogenous zones, the perspective of Merleau-Ponty does not address the social process of interaction through which sexuality and the Self are developed. To understand the experiences of the women in this study, it seems appropriate to include a psychosocial perspective on sexuality.

2.4.2 BIOPSYCHOSOCIAL PERSPECTIVE ON SEXUALITY

Almås & Benestad emphasize the importance of seeing sexuality from a systems-based perspective, both in terms of an individual level (body systems, psyche, spiritual) and socio-culturally. One the individual level, sexuality develops as one learns to understand one's body and sexual feelings (Almås & Benestad, 2017, p. 40). Feminist scholars point out that women's psyches are anchored in their bodies as well as in culture, and that considering women's context is crucial to understanding women's lived experiences (Tolman, 2012, p.

748). Sexuality affects the relationships we have with ourselves and others as we strive to find belonging during the formation of our sexual identity (Almås & Benestad, 2017, p. 52-53). When sexuality is welcomed and given space it will thrive and grow, and when suppressed, can easily become handicapped and difficult (Almås & Benestad, 2017, p. 45).

Norms create expectations about how one will be received by others (Ibid). In the context of this study, both norms for female sexuality and norms for health and illness are relevant. Heterosexual women are subject to norms for sexual behaviour which are centred around male sexual arousal and pleasure, often referred to as the "heteronormative discourse" (Tolman, 2012, p. 748). When discovering that their own experience is in violation of the socially dominating norms, it's not uncommon for young women to suppress their authentic self in order to preserve relationships (Ibid).

Feminist researchers advocate for the view that desire is a part of the Self, *a knowing, feeling, experiencing self*, described in terms of sexual subjectivity and sexual agency (Tolman, 2012, p. 750). Sexual subjectivity refers to a person's identification as a sexual being by experiencing herself as such, who feels entitled to sexual pleasure and sexual safety, and who can make active sexual choices (Ibid.). Sexual subjectivity is a necessary component of sexual agency in the sense that it affects one's ability to act in the world and to feel like one can will things and make them happen (Ibid.). Desire is related to this as a sense of entitlement to that which one has an appetite for, or a yearning or a worthy goal to stretch towards (Ibid.).

2.4.3 BIOMEDICAL PERSPECTIVE ON SEXUALITY

From a biomedical perspective, sexuality is viewed as one of the "natural functions", alongside sleep, digestion etc. (Almås & Benestad, 2017, p. 50-51). Libido, arousal and orgasm are explained as physiological processes and seen as sexual functions which become subject to medicalization (Ibid). For example, reduced libido is termed a dysfunction. Social or psychological factors are not considered within this view, nor is sexuality recognized as an aspect of existence, or someone's lived experience. Although the contemporary definition of sexuality recognizes its complexity, the biomedical perspective still affects the way sexuality is understood due to medicalization (Ibid.). Women and men come to view their sexual challenges as dysfunctions that need to be fixed. As "curing" is the domain of the medical institutions, the individual can become disengaged from their own healing process (Ibid.).

2.4.4 SEXUAL HEALTH

Several authors argue that defining sexual health is problematic as there will always be a risk that definitions become normative, and that somewhere in the multitude of sexual experiences, orientations and expressions, someone will feel left out (Almås & Benestad, 2017, p. 47). The increase in medicalization of female sexuality during recent years with the emergence of diagnoses like "hypoactive sexual desire disorder" (HSDD) is problematic, as it fails to acknowledge the social and cultural contexts for women's sexual difficulties by creating normative expectations for their sexual behaviour (Braksmajer, 2018, p. 420).

In light of this, a biomedical perspective is inappropriate for understanding and treating sexual problems as their aetiology may be multifactorial (Almås & Benestad, 2017, p. 50; Rosenbaum, Bernard & Wilhite, 2015, p. 551).

2.5 RELEVANT PREVIOUS RESEARCH ON PVD

As mentioned, sensitization plays an important role in PVD due to depression, fear of pain, stress, catastrophizing and the tendency to misinterpret bodily sensations (Pukall & Cahill, 2014), leading to fear-avoidant behaviour (Chisari & Chilcot, 2017, p. 84). Although some women continue to be sexually intimate in ways that don't involve penetration, others avoid sexual contact with their partner (Braksmajer, 2018, p. 430; Groven et al., 2016, p. 825).

Women are torn between the desire to meet their partner's sexual needs and the desire to avoid the emotional and physical suffering of enduring painful intercourse (Ayling & Ussher, 2008 cited in Leclerc, Bergeron, Brassard, Bélanger, Steben & Lambert, 2015, p. 1562). Quantitative studies focusing on sexual communication have seen correlations between improved sexual communication and a reduction in pain and psychological symptoms (Awada, Bergeron, Steben, Hainault & McDuff, 2014, p. 1278-1280; Rancourt, Rosen, Bergeron & Nealis, 2016, p. 1940).

From their conversations with eight women suffering from PVD, Groven et al. found that women with PVD want to be able to have sex again (2016, pp. 825 & 830). However, women with vestibulodynia consistently report reduced sexual arousal and desire, lower frequency of intercourse, difficulty achieving orgasm and decreased sexual satisfaction (Desrochers et al., 2010, p. 106-107).

Any vulvar disease or dysfunction may disturb a woman's sense of self, as the vulva is associated with privacy, femininity and sexuality (Rosenbaum, Bernard & Wilhite, 2015, p.

551). Qualitative studies to date show that women with PVD are affected by the heteronormative discourse, for example by feeling like intercourse is a duty (Groven et al., 2016, 825; Braksmajer, 2018, p. 424). Being conflicted about one's body because of their inability to enjoy intercourse, makes advocating for one's needs during sex difficult (Groven et.al., 2016, pp. 825-833). While enduring painful sex can be a protective response to the perceived failure to perform as expected, it is associated with increased pain (Leclerc et al., 2015, p. 1562).

On the positive side, Groven et al. found that through exploration and body-awareness, women with PVD had come to find their body as meaningful and expressive, discovering potentials for pleasure as well as an opportunity to improve their sense of self (2016, p. 826). In their quantitative study, Katy Bois and colleagues found that greater relationship intimacy and sexual intimacy were associated with greater sexual satisfaction and sexual function, as well as higher confidence that one can cope despite the pain (Bois et al., 2013, p. 2033).

Recent studies show that treatment that targets PVD women's beliefs about pain positively impacts their sexual functioning as well as how they experience the quality of their relationship with respect to cohesion, consensus, satisfaction and affectional expression (Craven et al., 2016, pp. 530-535).

2.6 NORWEGIAN PSYCHOMOTOR PHYSIOTHERAPY

Norwegian Psychomotor Physiotherapy (NPMF) is the result of the collaboration between a physiotherapist (Aadel Bülow-Hansen) and a psychiatrist (Trygve Braatøy) during the years 1940's and early 1950's (Bunkan, 2014, p. 259). In NPMF, the treatment is targeted at facilitating an adjustment of the body toward better coping and health, with specific emphasis on the breath (Ibid.). The modality addresses the interconnectedness of respiration, muscle tension, posture, movement and psycho-emotional state (Øvreberg & Andersen, 2016, pp. 25-30). It is process-oriented, in the sense that the patient becomes engaged in their healing journey through techniques that strengthens mind-body awareness and coping resources (Bunkan, 2014, p. 262). Foundational to the method is the view of the body as meaningful and expressive of people's lived experiences (Gretland, 2007, pp. 96 & 177; Øvreberg & Andersen, 2016, pp. 23-24).

3 METHOD

This chapter presents my preconceived understanding, the method chosen and scientific approach to research and analysis, as well as challenges and ethical concerns. Information about how literature was gathered is also included.

3.1 THE SAMPLE POPULATION

All nine women who were interviewed in this study came across as heterosexual. This is reflected in the theoretical foundation presented here. They were different stages of their healing process. Aged between 23-38, all were at a stage in life associated with higher sexual activity than later in life, as well as motherhood. This is important to consider, as findings may be uniquely tied to these contextual factors.

3.2 BASIS FOR CHOICE OF METHOD

This study seeks to contribute better insight and understanding of how women with this diagnosis experience, think and feel about a specific phenomenon (sexuality). Inherent in this type of qualitative research is the phenomenological view that reality is what people experience as real, and that every human action has meaning (Kvale & Brinkmann, 2009). According to hermeneutic philosophy, scientific studies of human experiences (in the world) must be based on those human beings' experience of being in the world and of its phenomena (Järvinen et al. 2017, p. 157). The method for gathering and processing data in this study is grounded in these philosophical perspectives.

3.3 SCIENTIFIC GROUND

3.3.1 PHENOMENOLOGICAL/HERMENEUTIC APPROACH

From a theoretical perspective, all qualitative research is based on phenomenological and hermeneutic principles in the sense that it seeks to develop empirically based knowledge (Malterud, 2017, p. 29). Phenomenological method aims at understanding phenomena in and of themselves instead of relating them to mechanical conditions (Kvale & Brinkmann, 2014, p. 46). This makes the approach particularly useful in research that seeks to encompass knowledge conveyed by and experienced through the body (Engelsrud, 2006, pp. 30-34).

According to hermeneutic philosophy, scientific studies of human experiences (in the world) must be based on those human beings' experience of being in the world and of its phenomena (Järvinen & Mik-Meyer 2017, p. 157). Hermeneutic interpretation is an inductive process where empirical data from individuals contribute insight into the area of research. Context and self-reflection on the part of the person analysing the data are considered important in this process, as our preconceived understanding lays the foundations for how we perceive (Kvale & Brinkmann, 2014, chapter 12). Through the *hermeneutic cycle* of interpretation and analysis, qualitative data go through a process of abstraction so as to extract meaning that can be applied to other individuals (Malterud, 2017, p. 28).

3.3.2 QUALITATIVE RESEARCH INTERVIEW

A qualitative, semi-structured interview is well suited for the present research question as it allows the informants to talk about sexuality from their own perspective (Malterud, 2017, chapter 13; Kvale & Brinkmann, 2014, p. 47). Simultaneously, the interviewer maintains the opportunity to guide the conversation using a list of questions (interview guide) so as to ensure it stays within the range of the research topic (Malterud, 2017, p. 135).

Although this type of conversation can bear resemblance with a casual conversation, the different roles of the two persons make for an uneven distribution of power. As an interviewer it’s important to be aware of this imbalance so as to make sure the interviewee is given enough freedom to speak freely and volunteer new information that the interviewer may not anticipate (Kvale & Brinkmann, 2014, p. 47). Throughout the conversation, the interviewer follows up with questions that seek to clarify aspects of the interviewee’s experiences so as to see them from the perspective of the interviewee (Ibid). Receiving what the interviewee is saying with a naïve openness is necessary in order to not let one’s preconceived understanding get in the way of seeing the phenomenon from the interviewee’s perspective.

3.4 PRECONCEIVED UNDERSTANDING OF THE TOPIC

While it’s not given that the women in this sample identify as heterosexual, I have assumed that they do because of their focusing on sexuality in the context of heterosexual relationships. It may be that there are variations of sexual orientation within the group, which adds to the complexity of the findings, but remain unidentified. Being a woman, my sexuality is just as much subject to my experiences and the influence of socio-cultural norms as the participants in the study, which will surely influence the study. I may over-emphasize or overlook certain phenomena or fail to see certain perspectives.

During my foundational physiotherapy training I learned to look at the body predominantly from a biomedical perspective, although my later training in Norwegian psychomotor physiotherapy was based in a bio-psycho-social perspective. As Norwegian psychomotor physiotherapy has been criticized for the limited scientific studies that exist to document its validity and effectiveness, I have noticed a tendency in myself to feel like I need to justify my work from a biomedical viewpoint. Also, being more used to reading quantitative studies on PVD over the past few years of working with this patient group, I have become more accustomed to the structure, logic and language that characterizes quantitative research.

In treating women who have experienced sexual abuse and non-consensual crossing of boundaries, I am careful not to overstep the boundaries of my patients. As an interviewer, I think this approach may limit the gathering of relevant information. As this topic engages me emotionally, I may mix up my own emotional and physical responses and those of the interviewee, misinterpreting them or fail to notice when our perspectives differ.

3.5 ETHICAL CONCERNS

3.5.1 ETHICAL REQUIREMENTS

Permission to conduct the research project was granted by the Norwegian Regional Committee for Medical and Health Research Ethics. Written information about the study and interview procedure were provided to potential participants along with an invitation to participate, which informed about the option to withdraw at any time without needing to explain why. They were also assured that all material would be anonymized. Before each interview, informed, written consent was obtained from each participant. They also agreed that the interviews be tape recorded and transcribed.

3.5.2 THEME AND RESEARCH QUESTION

In qualitative research the interviewer gains insight into topics that are often sensitive. Particular caution is necessary when the participant belongs to a vulnerable group (Malterud, 2017, p. 211). The topic of sexuality can be particularly challenging for these women, as they associate sex with pain and negative feelings (Groven et al., 2016, p. 825). Heed was taken to facilitate that the participant develop trust in me in order to feel comfortable and safe and I did my best to stay sensitive to the interviewee’s feelings and respect their boundaries. Time and type of questions to get the conversation going were adapted to the needs of each individual. Participants were given the freedom to refrain from answering, and to talk about other topics for a while if it made them feel more comfortable.

Qualitative interviews can potentially leave the interviewee with new insights into their own situation (Malterud, 2017, p. 213). I was aware that this might require support from a skilled professional. Participants were encouraged to bring any new insights to their therapist, and to contact me if they needed additional support. Agreement with a clinical psychologist was obtained for referral of participants should they express the need for additional support. No participant did however.

3.5.3 MY ROLE AS A RESEARCHER

Throughout the process of interviewing, I was not only gathering data but also transitioning to the interviewer-role, developing news skills simultaneously. During the first 3-4 interviews I was more careful not to push the informant's boundaries than in later interviews. Being new in my role I didn't want participants to feel pressured or invaded, but prioritized building trust to facilitate open sharing of relevant information (Malterud, 2017, pp. 211-212). Part of establishing trust was also explaining to each participant that the information they were providing would be used solely for the purpose of research and that it would be anonymized and stored safely.

Being sensitive to the needs of the interviewee while simultaneously wanting to gather as much information as possible, I sometimes faced ethical dilemmas during the interviews. At times when the informant expressed sadness or other negative emotions I noticed myself changing the focus onto something else because I was concerned that the situation would otherwise become too taxing for the interviewee. It may be that additional relevant information could have been discovered had I not done this.

3.5.4 THE PARTICIPANTS

Being true to the intentions and perspectives of participants is an ethical consideration (Malterud, 2017, p. 212). These women were courageous and generous by showing up and sharing sensitive information about their private life. I have done my best to serve them justice by trying to understand their perspectives and present the results accordingly. Immediately after the interview, participants were encouraged to reach out if they felt the need to add or correct anything they had said during the interview. No-one did.

3.6 LITERATURE SEARCH

A literature search was conducted in the PsychINFO and MedLine databases, using the same search strategy. The search protocol is included in the appendix. The search yielded 52 and 51 results respectively, of which many where overlapping. These studies were used in the development of the study design and the interview guide. It also provided a theoretical background for the preliminary stages of analysis by way of informing the researcher's ability to identify meaningful units.

More literature was gathered as themes and categories came forth during the analysis. When the analysis was completed, a list of search words was made for a second literature search in preparation for the discussion. Please see appendix number 6 and 7 for search protocols.

3.7 SAMPLE AND RECRUITMENT

3.7.1 PURPOSIVE SAMPLE

Qualitative studies of particular demographics and phenomena require a strategic selection of participants to ensure that the material yielded is relevant, rich and varied (Malterud, 2017, p. 58). Inclusion criteria were set as follows: Participants must be between the ages of 18 and 40, diagnosed with PVD by a gynaecologist, undergoing treatment or have completed treatment. Using data from this age group is a way to ensure that the finding in the present study are a valid and relevant contribution to the body of predominantly quantitative research within the same age group.

The sample size reflects this strategic approach as well as the limitations of a master's degree project. Starting out, the intention was to include six participants. The preliminary analysis of the first five interviews revealed a wide heterogeneity within the material and the need for more data to ensure sufficiently rich information. Therefore, an additional three participants were recruited. This mode of selection, informed by the first stages of analysis is known as constant comparative method (Malterud, 2017, pp. 64-65).

3.7.2 RECRUITMENT OF PARTICIPANTS

Three specialists who work with this patient group (one physiotherapist, one gynaecologist and one dermatologist) were invited to help with the recruitment process. Information and invitation to participate in the study was provided by the specialist. Women who were interested were then contacted directly by me, upon which an interview was scheduled. Six participants were included via these connections. As the first few interviews had been conducted it became apparent that the ability to verbalize about sexuality varied between participants. Therefore, the decision was made to recruit three more participants from my own network of acquaintances.

3.8 THE INTERVIEW PROCESS

3.8.1 DEVELOPING THE INTERVIEW GUIDE

This interview guide was developed with the support of Gro Killi Haugstad, my first supervisor who is also experienced in qualitative research in this specific field. Questions were open-ended and concerned different areas of sexuality and associated psycho-social factors. In addition, the participants were invited to share any additional information important to them in terms of their relationship to sexuality.

The interview guide was tested in a pilot interview with an acquaintance who has experience from interview-based research, and who also has PVD. Upon feedback from her, the guide was edited accordingly. During the following five interviews unexpected relevant information was shared and the interview guide was adjusted again to ensure that the remaining interviews could bring to light more information about those topics. Adjusting the research method in this way is an important feature in research that seeks to unveil new information (Malterud, 2017, p. 217).

3.8.2 CONDUCTING THE INTERVIEWS

All nine interviews were conducted within a period of 3 months. Participants were welcomed into a warm environment with comfortable furniture, and offered tea, coffee or water to drink. One interview was done via video conference because the informant was unable to meet up in person. In every interview, the recording started after the purpose and procedure of the research project was reiterated and written consent was obtained. Informants were informed about the option to take a break or cancel their participation at any moment during the interview.

Conducting the pilot interview was helpful as a way to become familiar with the role of being an interviewer although I was aware that developing this role and the skills associated with qualitative research would require more training. The pilot interview was included in the material as it yielded valuable information.

There was a vast difference in how the participants expressed themselves verbally about sexuality. Some seemed to feel comfortable, sharing detailed descriptions of personal experiences, while others gave short and superficial statements. My way of handling this changed throughout the period of three months that the interviews took place. In the beginning I made sure not to push the informant for more information than she seemed comfortable sharing. After the first interview, the informant told me that I could have asked more follow-up questions because she had more information to share, especially about how she deals with the challenges of intimacy in her relationship. This helped me become aware that my careful approach might limit the richness in the data produced during the interviews. Becoming bolder in terms of asking more follow-up questions was a gradual process which allowed me to get a better understanding of the participants' perspectives.

As I became more confident, a sense of collaboration developed between myself and each participant. When the interviewee started a sentence without finishing, I remained quiet for some time before sharing what I guessed might be the continuation of her sentence as a way of asking if this is where she was heading. The interviewee would then continue, either by correcting me or by agreeing and elaborating. It seemed to work as a way for the interviewee to check out how she would be received and for me to express that I accepted and acknowledged what she wanted to share. Through this dynamic, the women shared more information than I had expected in the beginning of the project.

3.9 CHALLENGES

Recruiting participants from other clinicians meant that participants didn't have a chance to develop trust in me before the interview and for some, verbalizing about sexuality was challenging. Wanting to improve the chances of gathering material as rich and detailed as possible I chose to recruit the last three participants from my own network of acquaintances.

During interviews I sometimes found it difficult to discern who was most challenged in moments that evoked strong emotion: myself or the interviewee. Concerned that the power-dynamic in the relationship could make the interviewee feel pressured, I opted for the "safer" option of moving to another subject. This may have helped the interviewee feel comfortable, while preventing us from bringing relevant information to light during our conversation.

Mid-way through the project my supervisor was replaced. Discontinuing our collaboration was scary, because we had developed a relationship and a common understanding over the course of several meetings and I leaned on her guidance as I was going into the process of analysing the material. I felt attached to her because of her extensive experience from working with women with PVD both as a therapist and as a researcher.

Finding an appropriate way to organize results and selecting which ones to discuss has been another challenge. I have tried my best to balance the need to stay true to the research question with the need to honour the complexity of the material. Lastly, I would like to say that I have found it surprisingly challenging to adopt the phenomenological approach both as a way of understanding the material and as a way of writing.

3.10 PROCESSING THE MATERIAL

3.10.1 TRANSCRIPTION

Transcripts were made throughout the three months that the interviews took place. I tried to make transcripts as soon as possible after each interview so as to better capture the meaning of what was communicated while the interview experience was fresh in my mind. Early transcription gives the opportunity to make a preliminary analysis that can help the researcher discover important information that the informant volunteers without being asked (Malterud, 2017, chapter 3). Making these discoveries before the interview process is finished allowed me to adjust the interview guide to fit better with the reality of the interviewees.

Pauses, sighs, and laughter and emotional expressions were noted in addition to spoken words to transfer as much of the authentic communication as possible. Malterud emphasizes that the transcribed text must enable interpretation of the non-verbal cues that were communicated when the words were spoken (Malterud, 2017, p. 78). All transcripts were anonymized and titled with a false name, which made it easier to continue remembering the context and person behind the material. Malterud stresses the importance of maintaining the perspective of the informant when going through different stages of the analysis (Ibid.).

3.10.2 ANALYSIS

3.10.2.1 CHOICE OF ANALYTICAL METHOD

The material was analysed using a method called systematic text condensation (STC), a descriptive and explorative method for cross-case analysis of various types of qualitative data which enables the development of new descriptions and names of phenomena (Malterud, 2017, chapter 11). While STC is inspired by the phenomenological approach of Giorgi, it is also rooted in social constructivism as the researcher’s perspective is acknowledged as essential to the development of the material as well as throughout the process of analysis (Malterud, 2017, p.116). STC is a four-step procedure, through which the researcher attempts to grasp the essence of the interviewees’ lived experience (Malterud, 2017, chapter 11) of in this case, sexuality. As I started collaborating with the new supervisors during the initial stages of analysis, my procedure was shifted slightly as they became involved in the project.

The process of analysing was characterized by the hermeneutic approach of alternating between looking at details in the material close up and “zooming out” to see the bigger picture. A description of the process is given in the following section.

As a side note I would like to mention that the analysis began during the process of conducting the interviews as my first impressions of topics were formed, and as I adapted the interview guide along the way. Transcribing the interviews gave the opportunity to read between the lines of what the informants were really communicating.

3.10.2.2 THE PROCESS OF ANALYSIS STEP BY STEP

Step one was to develop an overview of the material by reading through each transcript. While reading I wrote down themes as they emerged. Then, each transcript was read through slowly with careful attention to all meaningful units which were marked with a colour in the transcript, so as to enable later location, and noted on a separate piece of paper. I looked at how the meaningful units corresponded with the list of preliminary themes and refined them to better represent the meaningful units. At this stage I did my best to look at the material with an open mind, attempting to put my preconceived understanding and research question to the side to limit the amount of bias in the subsequent stages of analysis and interpretation.

When my supervisor was replaced by two male supervisors with a background in psychiatric nursing and sociology, they read through the transcripts to become familiar with the research material. This proved useful in terms of identifying elements in the material that I would not have discovered otherwise. The next phase of analysis was to identify what the meaningful units were actually about. Using a hermeneutic approach, we moved between looking closely at meaningful units and “zooming out” to studying the themes, then “zoomed” back in to see if the themes represented the participants’ statements. Different ways to organize the material were drawn on a large white board. After meetings I continued with the “hermeneutic circle” approach to see if the map represented the participants’ empirical reality. Here is an example of how a meaningful unit was organized within a sub-category and a main category:

Meaningful unit	Sub-category	Main-category
Seeing one’s body as defect	Understanding pain and desire	Trusting oneself

This procedure was repeated three times before I settled on a set of categories and sub-categories that is summarized in table 3.10.2.3.

3.10.2.3TABLE OF RESULTS

Themes	Defining sexuality Being different Relationship to partner Understanding pain and desire Facing the pain during intimacy Transformation	
Code groups	Perception/experience of self and sexuality	Coping strategies
Sub categories	Focus on partner intimacy Understanding pain and desire Sexual Self and otherness Trust within the relationship	Creating distance Enduring and concealing pain Creating safe environment Relating to pain during sex Cultivating pleasure and intimacy
Main categories	Trusting oneself	Having control

4 RESULTS

The results are organized into two main categories titled “Trusting oneself” and “Having control” as these two topics stood out during the analysis.

4.1 TRUSTING ONESELF

All women spoke of different sources of influence in forming their relationship with sexuality, ranging from their own opinions and experiences and those of others. What they trusted as true varied within the sample. Each woman has had, or is having, a struggle to decide for herself what truth to trust and believe in and live by. The “truth” about sexuality was greatly influenced by the "truth" about the pain they were living with. The women's trust-relationship to different sources of influence were organized into four sub-categories.

4.1.1 WANTING TO MAKE INTERCOURSE WORK

Everyone had an idea of how sex with a partner could or should be, regardless of whether this matched their real experience or not. The common view was that intercourse is a requirement for a committed relationship. All participants had a longing for enjoyable, pain free partner intimacy. Those who were not sexually active, expressed having a longing to feel desire for partner intimacy. Talking about one's inability to engage in and enjoy partner intimacy brought up feelings of sadness. A participant said the following:

> *I can't even be a whore.*

Participants described experiencing their romantic relationship as being reduced to living together as best friends. One participant who chose to live alone said the following about the psychological impact of knowing she was unable to engage in sexual intercourse:

> *I'm quite good at stuffing down the negative thoughts because I know that if I feel into it too much, I'll sink into a deep darkness, and I'll struggle to get back up. I'm afraid I'll become really depressed if I allow myself to pay attention to how I really feel.*

Those who expressed themselves with more confidence defined intercourse as something more than physical penetration.

> *Sex isn't just physical. It's an emotional, energetic exchange. Its love making. And I know it requires safety.*

Coming to view intercourse in this way was tied to a process of developing one's confidence and sexual desire.

> *It was necessary for me to become independent, to learn to stand on my own feet, in order to realise what sexuality means to me. I realized I must take responsibility by discovering what I like and what I don't like and dare to express myself about it. I explored myself with my own hands, I collected erotic scenes in movies and books that felt right to me. Scenes that gave me a sense of recognition that this, this is the way I like it and want it to be in my life.*

Participants shared the experience that making sexual intimacy enjoyable was or had been challenging. Belief in the likelihood that pleasure could be felt during intercourse varied and seemed to depend on how one defined sexual intercourse and on sense of one's own value:

> *I know that sex is something extraordinary and meaningful. I want good sex. I know that if I accept bad sex, that's what I'll get because I used to do that for so long. Now I know that if I take the consequences of what I've learned from my body I can have amazing pleasure.*

4.1.2 UNDERSTANDING PAIN AND DESIRE

Defining one's own sexuality was very much also related to experiences of pain, pleasure and desire, and the meaning the participants attributed to these phenomena. For some, the pain they felt in their vaginal opening was purely a sign of physical disease. They expressed that it was psychologically taxing to feel the pain and live with the limitations it posed on their sexuality and intimate life. Other than that, they didn't attribute any psychological meaning to the emergence or maintaining of the pain. One participant who had experienced sexual abuse as a child said the following:

> *They sent me to a gynaecologist to confirm that it was nothing psychological. I was a 100% sure, I mean, nothing about the genitals is psychological. But I understand that they needed to examine me to rule it out. I think it started with that chlamydia infection two years ago. The pain has been there ever since, even though the chlamydia was gone after two weeks. If there is something psychological that is causing the pain… then that must be from experiences too far back in the past for me to remember. I can't understand what that could be.*

Most participants were finding it or had previously found it challenging to deal with the psychological aspects of the pain. Some had become convinced that their pain is both physical and psychological and believed their pain could guide them to make things better:

> *Every time my previous boyfriend gave me a hug I felt the tension and pain in my vagina. I froze with fear that he would get aroused because I couldn't have intercourse. He would always get so angry. That's when I realized that the pain was there to alert me that I wasn't safe in the relationship. Now, I see my pain as a wise warning mechanism from my body that something's not right. There's nothing wrong with me. The safer I feel, and the more pleasure I have, the less pain I feel. I have pain*

> *because I don't just accept whatever is thrown at me. It doesn't make me a bad lover. It actually makes me a really good lover.*

All the participants shared that the thought of painful sex made their desire drop. While some *knew* that pleasurable sex made them feel more desire, other participants were frustrated, thinking that lack of desire was a separate problem additional to the pain.

> *My desire just vanishes! Of course, I've wondered if it has something to do with the pain. But, sometimes I fear that my desire won't come back even if the pain goes away. I hate to admit this because it makes it seem like the pain is so damn psychological; when I have sex in places where I have no bad memories, I feel no pain at all.*

All participants had seen several health care practitioners before getting the right diagnosis. The struggle to be taken seriously and to get adequate information about the diagnosis has greatly impacted the way the informants trust and view their body and their sexuality.

> *The doctors didn't examine me, they just said, "it's in your head, you just need to relax and it'll go away". But how was I supposed to turn off something that's in my head?? (...) I felt like a part of me was defect because there was nothing I could do to control it or take it away. I know I wasn't as free in my exploration during those years as I might have been if I'd been examined and given the tools I have now.*

Very few had had any type of support in dealing with their difficulties with partner intimacy. Some had concluded that turning to medical doctors for help is pointless:

> *My experience in meeting health care personnel regarding this issue is that they have less knowledge than I do. They don't share my holistic view. Talking about challenges around intimacy with them is out of the question for me. It's too vulnerable, and I know I would end up feeling worse afterwards.*

4.1.3 SEXUAL SELF AND OTHERNESS

The majority of the participants shared that the relationship to women was very important to them in relating to the topic of sexuality. Some were concerned about being different from other women, seeing their own sexuality as less valuable because they were unable to enjoy intimacy in the same way. Being different was associated with not being able to participate with others. Some admitted to pretending to be more sexually active.

> *I too want to take part in sharing sensational sex stories. It's like I'm sitting outside looking in at the conversation. I have nothing to share, and I can't tell them why because that would make them feel like they have to be careful talking about sex around me. I don't want to cause any awkwardness.*

Comparing oneself to others lead to frustration at not being or having what others have:

> *The elder women in my family have told me that sex shouldn't be hard. It's supposed to easy, and lovely, not a struggle. I'm frustrated. I wish I could have sex whenever I wanted like everybody else.*

Participants who had accepted that their sexuality might be different from other women, were critical of the way female sexuality is presented my other women and the media:

> *It's a good thing that I am so sensitive. I can't just be fucked hard like they do in porn. My sexuality is refined, like a Ferrari. If I'm treated with respect, presence and with skilful movement and touch, the pleasure can be amazing on every level for both me and my partner. But, if you drive a Ferrari like you would a tractor, you wreck it. A woman's vagina is a sacred place. We know it's wrong to step into church with a chainsaw. We need to understand that that applies to the vagina too.*

The participants who had had conversations with other women who live with PVD mentioned this as a very supportive experience, contributing to reassurance that they were not alone, and even feeling more hopeful for the future.

> *It's been so wonderful to meet someone who knows exactly what I'm going through. I don't feel so alone. It doesn't take away the pain, but it reduces the psychological stress around it.*

4.1.4 TRUST WITHIN THE RELATIONSHIP

The analysis revealed that trusting oneself and the partner was essential for these women to feel safe in the relationship. Trusting oneself meant to feel confident that one would not get involved in destructive relationship dynamics with respect to sexual intimacy. Trusting oneself as able to stop a sexual activity when painful stood out as an important challenge:

> *When I met him I'd already decided I was over and done with having painful, bad sex. But it's really hard when you're in the middle of the situation. I might be able to be honest about the pain on a good day, but not if I'm having a bad one.*

Most of the women described a transition from having trusted men less in the past, to developing increasing trust in their current partner. This process of developing trust implied taking risks and moving beyond one's comfort zone:

> *I must push my own boundaries and do things even though I find it super-uncomfortable. I was so incredibly tired and depressed the first three months. I realize it was because of all the effort it caused me to establish this relationship and do all those things that felt so unsafe and uncomfortable.*

Trusting partner meant to feel certain that he loved her, that he understood the impact of her pain and that he would respect her boundaries:

> *I need to trust that he really loves me. Before we had sex the first time he showed me that he wanted to get to know* ***all of me****. He prioritized talking with me on the phone until way past midnight although he needed to get up super early. I told him that I was anxious about sex because it always hurts, and he said, «I will never push myself onto you. You can trust me on that».*

The women who were in the process of developing their sexuality and ability to express their truth felt increasingly confident about their value and what they bring to the relationship:

> *I know I challenge him, but in a good way. I express myself more than he has ever experienced with previous partners.*

4.2 HAVING CONTROL

The analysis showed that in terms of coping, participants used different strategies for having control, ranging from avoiding sexual intimacy to moving toward it. The strategies are organized into five sub-categories and presented as such.

4.2.1 CREATING DISTANCE

The analysis showed that participants found it difficult to be physically intimate without also risking physical and emotional pain. In attempting to maintain control they created distance in different ways. This participant explains how she tries to avoid her partner getting aroused:

> *I avoid hugging and kissing out of fear of waking his libido. I dress less sexy, choose the ugliest underwear, drop shaving my armpits and legs… I'll wrap myself in a towel to avoid him seeing me naked when I get out of the shower.*

All the informants experienced that when physical intimacy is compromised, emotional intimacy suffers in the relationship. This participant explains how she suppresses the sadness she feels at not having emotional intimacy in her life:

> *Most of all I miss the emotional intimacy. But I don't think anyone would accept me and love me just the way I am. It's very, very hard. I'm quite good at pushing these painful thoughts aside. I fear I'll get very depressed otherwise.*

Having a partner who struggles with sexuality himself, some participants were relieved at not being the only one in the couple who struggles sexually:

> *I was so relieved when I understood that he's lost interested in sex because of the pills he's taking. Of course, I would love to explore other types of intimacy in the future, but unfortunately that's impossible right now.*

Believing one must make intercourse work in order for a relationship to be successful, another way to create distance was by not committing fully to a partner.

> *I feel that we've stagnated where we are now, so I think we might just have to be friends instead. When we're intimate and we both arrive at a point where we want to have intercourse I've had to stop every time. It triggers my painful memories and I can't continue. He's very understanding and easy going, but I don't think a relationship will work as long as we can't get past this. I haven't told him why intercourse is so challenging for me. I think I should if we decide to continue being together. I think it's necessary for us to make that part of intimacy work.*

4.2.2 ENDURING AND CONCEALING PAIN

Most participants were finding it difficult to tell their partner about their pain when it occurred during intercourse or other sexual activity. While some solved this by avoiding sexual intimacy completely, others were attempting to find ways to make intercourse less painful, or pain free. Desire to be normal and fear of rejection were strong motivations for keeping quiet about the pain, and enduring painful intercourse seemed the lesser of two evils:

> *Although I know he probably doesn't feel the same way as my previous partner who cheated on me and finally left me, I don't want to risk it. I make sure we have sex once a week. That way I know that at least our intercourse rate is like the average couple. I also believe it's important to not let it die down for my own sake. It hurts every time*

> *and I do feel nauseous, like that creepy feeling you can have when you know that, "this is not ok". But I don't feel like I have a choice.*

Stopping intercourse seemed like an "impossible" situation where one has no tools for coping:

> *If I stop, then what am I supposed to do? I mean, when I'm in pain I don't want anything to happen to me in terms of touch or stimulation. - And what about him? Am I supposed to help him get to climax? I don't want to do that either when I'm in pain. I just want it to end… So, I just let it continue, and hope for it to end soon. I wish I could say I look forward to having sex, but I don't. I expect it to hurt. If you asked me what I'd rather do: have sex, or sit on the couch with him, eating sweets and watching a movie, I would definitely do the latter.*

Those who were actively trying to change the habit of suffering through painful intercourse, experienced overwhelm in the situation, and a state of "freeze", unable to find words.

> *I really feel like I am a problem in those situations. My experience is that everything is slowing down. I tense up. I become like, "eh... I don't know…", kind of unable to make any decisions. I can't be present in my body. It's overwhelming, like a wave that suddenly hits me: Bang! And I can get quite irrational, and think things like, "no, there's no point, we should just stop everything. We can never have sex again".*

These experiences brought up feelings of shame and guilt, and the need to escape:

> *I run and hide in the bathroom, under a towel. I just want to be alone with my shame.*

4.2.3 CREATING A SAFE ENVIRONMENT

The analysis showed that for the five participants who were sexually active with their partner, and who were committed to find ways to experience sex as pleasurable, establishing a safe environment for exploration was important. Feeling safe was emphasized as a necessary requirement to handle fear of pain during sexual intimacy, and to be in a state of open-mindedness so as to explore intimacy and experience pleasure. Making sure that their partner shared their own understanding of what was going on, and that he had the proper skills to handle it made them feel safe enough to face the pain and continue being intimate.

> *It makes a big difference how the partner reacts, because I'm so vulnerable in that situation. He needs to understand what's going on for me, and not freak out or take it as rejection. And it matters a lot how present he is, and the quality in his touch. If he's*

> *fully present in his body, my body will respond by opening up again. Otherwise, I tense up even more.*

These participants saw it as their responsibility to create the sex life they want in close collaboration with their partner. They were conscious that the quality of their sexual experience depended on how well they were able to communicate with their partner. However, having to teach the partner how to be supportive was difficult:

> *I need to teach him what's going on and what I need but I wish he could understand intuitively as it's challenging for me to be a teacher and a partner at the same time.*

Feeling vulnerable when speaking up about one's needs, it mattered how this was received by the partner. Appreciation, openness, acceptance and willingness to learn new things stood out as partner qualities that contributed to the feeling of being safe. This participant explains how her self-confidence grew when she realized her boyfriend had learned something from her:

> *I prefer to spend some time cuddling in bed after sex, to enjoy the resonance of what just happened. It really strengthens the intimacy for me. He told me that he appreciated me for showing him that because he really likes it too. I'm really happy that he can learn something from me, being much less experienced than him and all.*

Participants explained that the foundations for feeling safe are created outside of the sexual act itself. Safety came with feeling emotionally connected to the partner:

> *We practice sensing how the other person feels, by taking the other person's perspective. It makes us both feel that we are seen by the other, that we are being listened to. It makes us both feel safe with each other.*

Noticing the partner's presence and consideration through the quality of touch was another aspect that contributed to the feeling of being safe:

> *It's really important that he listens to me through his hands when he touches me. That he is fully present in his own body, and that he's able to control his own movements.*

4.2.4 RELATING TO THE PAIN DURING SEX

For the informants who were actively pursuing pleasurable sex / intercourse, two strategies stood out in terms of relating to the pain during intercourse. One was to train oneself to relax with mild pain, provided one viewed the pain as harmless:

> *It's important that I don't allow myself to become afraid of having sex again just because it hurts a little. I mean, the pain isn't dangerous. It just means that my infection is flaring up again.*

Four out of six sexually active participants were not attempting to endure any degree of pain. When encountering pain during sexual intimacy they would pause and process their experience. These participants saw the pain as a warning signal from the body that must be respected and were actively searching for emotional and physical pleasure in sexual intimacy. Practicing awareness of thoughts, feelings and physical sensations during sex, they discovered opportunities for alternative solutions and new sensations:

> *I've taught myself to notice it if I tense up when he's inside me. I'll notice that it begins to hurt and ask him to pause and wait a little until I am able to relax again. The pain might not come back if he begins to move very slowly and carefully. But, if I can't make the pain disappear, he needs to pull out, and that in itself can be excruciatingly painful. He's worked out a way to do it super slow and gently recently, and when he does it that way I hardly notice it. It's unbelievable! It wouldn't have worked with any of my previous partners because I felt resentment and lack of trust in them and wanted them to pull out as fast as possible. This guy I trust completely, so he can stay in there when we need to stop. It gives me an opportunity to discover better strategies when the pain arises during intercourse.*

Understanding their struggles with pain and partner intimacy as a result of their own decisions and behavioural patterns, these women felt like they had no other choice but to work on themselves and their relationship. This process was experienced as hard work:

> *It's really hard. It feels like a chore that I have to master. Having PVD means you have to work on yourself, you have to address all those behavioral patterns and beliefs you have and that's really heavy work. I wish I had support from someone. But I know there's no other way for me to make my life enjoyable. I have to do this.*

Changing the pattern of not communicating about pain was particularly difficult. Wanting to find control in overwhelming situations, participants were trying to become awareness of what triggers the pain, and the fear of pain. Ability to confront fear and shame depended on the caring presence of the partner. The participant who would run and hide under a towel in the bathroom to be alone with her shame explained it in this way:

> *The amazing thing is he'll come after me. He sits down next to me and just strokes my back. That's exactly what I need, because right there and then I'm like a child that needs comforting. The first time this happened he asked, «what just happened?» That's when I understood that he didn't mean to hurt me. And that he still loves me, even though he doesn't understand what I'm going through. That's when it becomes possible for me to talk about it.*

4.2.5 CULTIVATING CONNECTION AND INTIMACY

By working out how to handle overwhelming encounters with the pain, these women had discovered that by staying relaxed and open-minded they could have unexpected pleasure.

> *I've noticed that if I manage to stay relaxed and open minded to the possibility that the pain can change there and then, it does. He will try something different and then, all of a sudden: Eureka! It changes, and suddenly the pleasure is back.*

Focusing on sensation, in a non-judgmental way, rather than just pain, these participants were able to discover pleasurable sensations and desire:

> *Since my physiotherapist advised me to explore touching myself to become aware of what I feel, where it hurts and where it doesn't hurt, my boyfriend and I have tried it out on each other. We just focus on touching each other, on just enjoying the pleasure, without trying to reach a climax or anything. I'll be lying down, trying to just relax and breathe while he is touching me. It actually works, I'm actually happy that we can do this together, especially because I can sometimes feel my desire awakening! I get very emotional whenever I actually feel desire, because it happens so rarely.*

These participants used their awareness of what makes them feel unsafe to find strategies to prevent this from happening. The solution was to maintain connection with the partner during sexual intercourse or other sexual activity in various ways, and to make sure they felt that they had a sufficient level of control:

> *I reach for his hand if he gets too eager, too intense: Reminding him that I'm actually here and that this is about the two of us, not just the pleasure he feels in his penis. I prefer for us to be face to face, sitting up, with me on top. That way we can kiss and caress while we make love, and we are on the same level.*

Skin contact and staying as close as possible were strategies for communicating non-verbal cues for pleasure or pain and maintaining a sense of control during intimacy:

> *Skin contact makes me feel safe. I can make love in the traditional missionary position as long as I can feel his belly touching my belly. I feel that nothing too bad can happen if we're that much connected.*

Another participant explains:

> *When we're touching I know it's easier for him to notice it when I tense up… - That is, if I'm unable to tell him that I'm in pain.*

These participants had discovered a connection between being emotionally intimate, feeling desire and the potential for experiencing pleasure during intercourse:

> *I need to long for him to come inside me. I can't have any negative emotions toward him. If I do I must express myself and we need to solve that first.*

5 DISCUSSION

I have chosen to focus this discussion on the women who choose to transform their relationship to pain and themselves. Although these findings do not represent some of the women in the sample, their reality provides context for understanding how difficult this endeavor is.

5.1 WANTING TO MAKE INTERCOURSE WORK

The belief that intercourse is a premise for a successful relationship may imply that norms for hetero-sexuality have become internalized, especially when inability to have intercourse is associated with reduced potential for experiencing love and intimacy (Groven et al., 2016, 825). Stumm writes about how sexuality can become narrow-minded, blocked when the focus is extreme (Stumm, 2015, p. 153). Perhaps dissatisfaction at feeling like one is living with one's best friend may come from an unmet desire for sexual intimacy that could otherwise have been if one felt that intercourse was not the "ultimate" way to have sex? Whatever the reason, focusing on the one sexual activity that provokes the pain seems to form a negative association to both partner intimacy and to one's body as they become reminders of one's inability and of what one cannot have. Longing to have the desire for partner intimacy may be an expression of how deeply one is missing it, yet it implies that one is focusing on something about oneself that one wishes would be different. When partner intimacy seems “impossible” to achieve, it seems that the next thing to try and change is oneself. How would it help to discover that other sexual activities could serve in terms of meeting the need for intimacy?

The capability to enjoy intercourse seems to be related to wanting to be fully realized as a woman and fully capable of expressing love, like Groven et al. (2016, pp. 827-833) found in their study titled “Will I ever be a true woman?”. While this too may come from internalized heteronormative discourses for partner sexuality, it may also be a longing to experience being in that type of union where a loved one is entering into the most precious and sacred part of one’s body, as an act that confirms that the partner is welcomed and embraced at the core of one’s being. Phenomenologically, this gives intercourse a meaning and purpose that goes beyond the male-centred view of intercourse that dominates the heteronormative discourse (Burkett & Hamilton, 2012, p. 823). The statement, *I can’t even be a whore*, can be interpreted as an expression of the dissatisfaction in not being able to engage in intercourse as a sacred act by pointing out that one isn’t even capable of “misusing” it. This dimension may be overlooked by clinicians and therapists if they consider women’s wanting to make intercourse work as solely a product of internalized heteronormativity. One should think that acknowledging this dimension is key to supporting women’s sexual subjectivity.

Coming to see one’s womb and vagina as sacred ground and a container of bodily wisdom seemed to change the orientation toward intercourse as the value of oneself and one’s body is independent from one’s “ability to perform” intercourse. The focus on the partner and the relationship also shifts from what he expects and what is normal to “is he the right match for me? Do I want to invite him into my sacred space?” With this shift, the motivation to make intercourse work seems to come from a desire to unite with a loved one in a way that is emotionally intimate, as well as physical. Can it be that as researchers and therapists we fail to recognize these other dimensions of PVD women’s longing for ability to engage in intercourse because we see it predominantly as a product of negative heteronormative conditioning? If this is so, one may think it limits our ability to have conversations with them that confirm those dimensions as valuable and something they deserve to advocate for in life.

Claiming the right to discover and define one’s own sexual preferences seemed to transform motivation for being intimate with a partner. Seeking out sources of inspiration that give a feeling of resonance, of familiarity, there is a discovery of what one wants: of one’s sexual subjectivity (Tolman, 2012, pp. 749-750). Positive expectations and desire can begin to form, inspiring a movement *toward* that which one does want (Ibid). Experiencing that this transformation comes as a natural consequence of learning to *stand on one's own feet* may exemplify that desire can't be separated from desire for other things in life (Tolman, 2012, pp. 749-750; Merleau-Ponty, chapter 5), and that it is integral to developing sexual subjectivity (Tolman, 2012, p. 750). As sexual subjectivity is a necessary component of sexual agency (Ibid.), this may explain why the women in this sample who express their sexual desires and preferences in most detail and with the most confidence also stand out in terms of their courage (and skills) to go about and "negotiate risk and pursue pleasure", to borrow the words of Mary Louise Rasmussen (Rasmussen 2012, p. 471).

5.2 UNDERSTANDING PAIN AND DESIRE

It came as no surprise that these women's relationship to sexuality was greatly influenced by their experience and view of their pain. However, statements such as "*nothing about the genitals is psychological*" may suggest that the dualistic view on the body has become internalized. Seeing the body as a machine that can break and get fixed, bodily sensations become signs of physical defect or illness which are the domain of the medical professional (Almås & Benestad, 2017; Engelsrud, 2006, p. 28). In response, it seems there is no reason to look to the body for guidance in how to deal with pain or illness. Following the same logic is the belief that anything psychological can be fixed through cognition which seems to impede the women's ability to accept that the pain might be *both physiological and psychological*.

Considering that the pain may have psychological aspects seems to trigger shame when not being able to *just fix it.* This is perhaps not so surprising when medical doctors have concluded it's *all in your head* because tests are fine, so *just relax and stop thinking about it.* Being left to one's own devices, one may choose to either ignore one's experience or defy the dualistic logic and try to make sense of one's bodily experiences. Unable to *just fix it* or turn off *something that's in my head* one is likely to see oneself as a failure. Hating to admit that intercourse can be pain-free in places where one has no negative memories indicate that there is a resistance to embracing that the pain may have psychological driving factors to it. Instead of celebrating and exploring the potential for having more pain-free sex, it seems there is contempt for the body as these experiences trigger the shame (Farstad, 2026, p. 52.)

There seems to be a connection between understanding the pain as purely physical and pathologizing one's lack of desire. The lived experience of desire is reduced to a dysfunction of the “machine-body”: an object (Braksmajer, 2018, p. 429; Almås & Benestad, 2017, chapter 3). While discarding the inherent wisdom in one’s bodily experience, one looks to the outside for an explanation and a remedy (Ibid). According to Merleau-Ponty, for someone who is suffering, it is only natural that sexual stimuli are not followed up by an active sexual response simply because the person is not engaged with what is going on. They are not living in the sexual situation, and therefore do not respond sexually (Merleau-Ponty, 1994, p. 115).

When the psychological factors of the pain are embraced as meaningful it seems women are capable of using their experiences as resources to know themselves better, and to develop more healthy relationships. This will be discussed in points 5.7, 5.8 and 5.9. Orientating towards the pain as a wise warning signal from the body requires trusting one’s own experience and taking a step away from those who advocate the biomedical perspective and who are meant to provide help and support when one is suffering and feeling vulnerable. This takes courage as it means stepping into an unknown landscape alone where sources of help and support may have to be invented. Awareness of connections between a given situation, one’s bodily sensations and feelings makes it possible to understand the meaning of the pain (Groven et al., 2016, p. 826). With this orientation toward the pain, one can move from seeing oneself as the problem to realizing that something about the situation must change in order for oneself to feel good: Being connected to and accepting of her authentic experience seems to facilitate the development of sexual agency.

Similar to the “just relax and stop thinking about it”-approach to achieving relief from “psychological pain”, the “just say no” -discourse around women’s sexual consent is deeply problematic (Burkett & Hamilton, 2012, pp. 815-817). This discourse is based on a premise that the woman should be a *hyper-responsible citizen*, capable of negotiating sexual consent regardless of her contextual factors (Ibid). The reality for the women in this sample is that it is *really difficult* for them to say no to painful intercourse. Even though they struggle to be authentic and honest about their pain, they expect themselves to desire partner intimacy. According to the postfeminist “just say no”-discourse, once they have suffered through a painful intercourse, these women only have themselves to blame when they experience negative loss of desire (Burkett & Hamilton, 2012, p. 819). Perhaps this may explain why there is a tendency not to accept decreased desire as a natural effect of pain? According to both the medical and post-feminist discourses, everything *should be* in order. After all, you should be able to switch off the process between your ears that’s causing the pain, and you should have *just said no* if you didn’t want the sex (Burkett & Hamilton, 2012, pp. 815-817).

Instead, it seems one feels compelled to finish what's started (Burkett & Hamilton, 2012, p. 824) despite feeling nauseous and knowing that *this is not ok,* because it feels like one *has no choice*. Unsure why desire *just vanishes*, and anxious that lack of "real sex" will threaten the relationship, it seems that the compulsion to continue suffering through intercourse is reinforced. The present findings indicate that much of the negotiation of sexual consent is happening behind closed lips. Seen through the lens of Brené Brown's work, it seems that in reality, negotiating sexual consent means to negotiate needs for being pain free, accepted and loved within conditions that claim these needs to be mutually excluding (Brown, 2017, p. 33). The potential traumatizing effect of facing pain under these conditions is discussed in part 5.6.

Finding the pain meaningful seemed to make it easier to also accept that reduced desire was a consequence of painful sex. Rather that feeling conflicted or confused, there seemed to be a sadness at missing desire as an essential part of being alive, fully experienced and expressed. In becoming more trusting of one's bodily experiences it seems easier to take a stand against norms that have affected not just what one has been doing with one's body, but also how one has come to *experience* it (Gretland, 2007, page 68). Concluding in a proud and clear voice that *there is nothing wrong with me* seems to be coming from trusting this embodied knowledge. In taking a leap that involves risking social rejection, the Self has become grounded in a more positive, empowering identity as *a really good lover.*

5.3 SEXUAL SELF AND OTHERNESS – TOWARD A SELF-CREATED SEXUAL SELF

Discarded shame makes good compost for cultivating dignity.

The findings indicate that the way women come to view themselves and their sexuality is impacted by how they relate to perceived differences between their own sexual experience and those of other women. Being different becomes a source of separation when it threatens one's sense of belonging to the group, to be loved and accepted (Brown, 2017, chapter 2). Brown writes that the pain of not belonging is one of the most dangerous types of emotional hurt, in the sense that "it can break our heart, our spirit, and our sense of self-worth" (Ibid). Brown found that what people try to achieve is "to be part of something – to experience real connection with others – but not at the cost of their authenticity, freedom or power" (Ibid). As the participants in this study compromise their authenticity in order to fit in, one can imagine the emotional pain they are living with.

Social rejection leads to shame as one comes to see oneself as wrong in the eyes of others (Huseby, 2017, pp. 14-15). The pain of shame is existential and can lead people to reject their authenticity in an attempt to avoid it (Brown, 2017, chapter 2). Part of the shame lies in the awareness of one's lack of knowledge (Frønes, 2001, p. 72), which may explain why it seems impossible to reveal sexual limitations. Rather, it becomes important to hide one's incapacity and lack of knowledge about sex. When social participation is associated with having to sacrifice one's dignity and integrity (Brown, 2017, chapter 2), it may seem like a minefield, and the effort to avoid exposure exhausting. While avoiding social rejection, the ability to connect to others is hampered (Ibid) and these women miss out on the opportunity to correct any misunderstandings about what others find acceptable, to saturate any curiosity about sexuality and to receive support from friends that may turn out to be empathic and understanding. The idea that one is *wrong* remains uncontested, and shame and loneliness can thrive (Brown, 2017, p. 54).

Admitting to not being sexually realized can challenge needs for self-acceptance and belonging as it is associated with social status in today's society (Salomonsen, 2001, p. 81-82). The tendency to objectify oneself, instead of consulting and embracing one's own experiences may illustrate the paradox that it may be even harder to develop "true belonging" and sexual subjectivity in a time when being a sexually realized woman is socially acceptable. Unable to even qualify as *a whore*, the sexual Self remains defined by its shortcomings and a source of separation from others.

Brown's research also revealed that when people were surrounded by "us versus them-cultures" that create feelings of spiritual disconnection, they felt forced to make a choice between being loyal to a group or being loyal to themselves (Brown, 2017, p. 33). In this perspective, compromising authenticity can be understood as a way to adapt to the perceived premises for participation by not challenging the others' tolerance and comfort. After all, this allows a degree of participation without having to expose herself and risk rejection although one remains separated from the group on one level. As exposing one's difficulties with partner intimacy to others would confirm one's lived reality, concealing it can also be understood as a way to protect oneself from negative feelings about that reality: belonging with others in an inauthentic way may be necessary while one is not yet ready to face those negative feelings and accept and love oneself fully. Connecting with someone else who has PVD seems to have the same positive effect as for people with sexual orientations different from heteronormativity who connect with each other: belonging confirms that one’s sexual orientation is not a symptom of illness, or of being wrong (Almås & Benestad, 2017, p. 56).

Being accepting of one’s own sexuality as different seemed to make it possible to (re)define one’s sexual Self through a conscious and deliberate process of self-creation, similar to what researcher have described (Beres & Farvid, 2010, p. 378; Rasmussen 2012, p. 471; Tolman, 2012, p. 753). This process included taking a critical look at, and eventually dismissing the social norms which have become Self-defining. The women who had accepted their sexuality as different felt less urgency to “fit in” and focused less on their “otherness”. It would seem that Self-acceptance brings relief from some of the pressures that create shame, insecurity and loneliness in living on the “outside”. Redefining their lived reality as acceptable, they found a place and identity for true belonging (Brown, 2017, p. 40).

This self-created Self also seemed to have a kind of dignity and pride in being able to care for itself, for example by not accepting painful experiences or to live in fear of pain. Being in the process of designing one’s sexual Self seemed to enable a transformation of destructive patterns of thought and behaviour which will be discussed in parts 5.7-5.9. This finding may suggest that developing sexual subjectivity and true belonging are even more important than being accepted by others. However, the finding also illustrates how perceived distance and difference from “others” make developing sexual subjectivity in adulthood so challenging.

5.4 TRUST WITHIN THE RELATIONSHIP

Believing that intercourse is a condition for a man’s ability to love, and that performing intercourse makes a woman lovable, it’s no wonder that these women emphasize that they need to trust that their partner *really loves* their entire being. Having experienced that fear of rejection causes one to hold back from intimacy, it makes sense that they emphasize trust as a requirement for cultivating a relationship and feeling safe in it.

As the results show, developing trust within the relationship was a matter of both trusting oneself and the partner. It seems that being in a romantic relationship is associated with confrontation and risk of rejection as sexual expectations and needs must be negotiated. Trusting oneself not to revert to the destructive pattern of enduring painful intercourse and lie about the pain again seems to run parallel to developing Self-worth, sexual subjectivity and sexual assertiveness which will be discussed further in later sections.

As this change impacts both people in the relationship, these women need to trust that the relationship unit can accommodate their growth process; That there is room to discover feelings and needs that have previously been neglected, accept them, mourn past losses and pain and discover ways to express and meet those needs in the now (Rosenberg, 2003, pp. 132-133). It may seem that having a partner who openly welcomes and celebrates one's growing sexual agency is necessary to dare embarking on this type of journey. Saying that breaking old patterns is difficult *on a bad day* may indicate how challenging it is to be consequent, and that having a supportive partner is imperative. As breaking old patterns means revealing one's shame to the partner (Brown, 2017, p. 32), one needs to trust he will not chime in with one's own negative self-talk. There must be room to try and to fail as many times as needed to form a new behavioural pattern that is in harmony with an empowered Self. Acknowledging that one is adding value by daring to be vulnerable seems to improve confidence in one's ability to assert boundaries when facing potential confrontation.

The results show that in realizing the importance of developing ability to trust, women go beyond their comfort zone as a form of self-induced exposure therapy. Like shame, trust is a product of how we are received by others (Huseby, 2017, chapter 1). Based on his work with abandonment trauma, psychiatrist Tormod Huseby has found that in order to trust someone we need to experience them as generous, humble and caring (Huseby, 2017, chapter 1). It seems that in order to discern whether their partner is trust-worthy or not, women consult their bodily experiences as they get to know their partner: Trustworthiness is felt in the body as a relaxation and opening up toward the partner. With this, it's safe to be vulnerable in front of the other person. When we are seen, we can trust that the other person loves who we really are (Brown, 2017, pp. 38-39). It seems necessary to reveal one's pain to the partner to find out if one is loved and accepted regardless of one's capability of having intercourse.

5.5 CREATING DISTANCE

Results revealed that participants find dealing with pain during sexual intimacy difficult without bringing harm to either oneself or the relationship. Creating distance in various ways may speak to how emotionally taxing this is. For example, by making oneself a less desirable sexual object in the eyes of the partner one becomes distanced from these difficult situations. However, there is also a disconnection from one's own body and femininity, as freedom of sexual/sensual expression are sacrificed. In a larger context, this may reflect how difficult it is for women to maintain the right to define their sexual Self in an environment that objectifies women's sexuality and sexualizes women's bodies (Burkett & Hamilton, 2012, p. 824).

This perspective may be helpful in understanding how making oneself less desirable is experienced. Moving and dressing in sensual and feminine ways may be associated with losing control, making it necessary to shut down the inspiration to be in the body and in the world in these ways. Seeing oneself as a sexual being may become difficult. Even though the pain started in a very small, specific area of her vulva, her entire body and her femininity become problematic and part of her suffering. The emotional pain of missing intimacy may become another reason to create distance from that which constitutes one's sexual Self.

Being relieved at discovering that one's partner has a sexual dysfunction can be another reflection of how hard it is to deal with sexual intimacy. Perhaps choosing to stay in such a relationship is a strategy to compensate for this difficulty? When both partners experience sexuality as challenging they can perhaps find mutuality and companionship in distancing from sexual intimacy together. However, having this in common may also make it even harder to find the motivation to work together to overcome those challenges. Besides, exploring other types of sexual intimacy can be associated with risk in itself, as intense pleasure is associated with losing control (Stumm, 2014, p. 153).

Another way of creating distance was by waiting to commit to a relationship until intercourse becomes possible. What can be the consequences of holding back from investing in emotional intimacy? Is it possible that waiting to commit also prevents one from feeling safe enough to explore sexuality without the felt pressure to make intercourse work?

5.6 ENDURING AND CONCEALING PAIN - WHY IS IT SO HARD TO BE HONEST?

Internalized norms for heterosexual behavior can be impactful in both forming and attempting to change the pattern of suffering through painful intercourse. However, this discussion will focus on the experience of being stuck in the pattern and trying to change it.

By not telling the partner that she's hurting, the woman is living in a dual reality: Outwardly her appearance and behaviour are like those of someone who is not in pain, perhaps even experiencing pleasure and enjoyment. This part of her is being seen and responded to by her partner. Inwardly, the pain continues to shape her experience in the moment, affecting her ability to be engaged in what is going on (Merleau-Ponty, 1994, p. 115). This effort feeds the relational aspect of the pain as she will associate it with being penetrated by the man she loves and wants to be loved by, yet he remains ignorant of this experience. Knowing that she has made herself a victim of his unintended pain affliction on her, she only has herself to blame for violating her own “sexual ethics” (Beres & Farvid, 2010, p. 379). However, she is saving her partner and relationship from potential conflict which may seem more dangerous.

When handling pain during sexual intimacy involves the body and emotions in such ways that bring experiences of overwhelm, freeze, and being unable to think clearly, it may indicate that the person is traumatized (Levine, 2008, p. 9). According to Levine, trauma is the result of experiences that are *perceived* as dangerous and life-threatening, and people become traumatized when their ability to respond to that perceived threat is in some way overwhelmed (Ibid).

It seems that answering “no” when the partner asks if one is in pain was more like a default action than a conscious choice. In trauma literature, this type of action is called a “response”: an action that one is *impelled* to take (van der Kolk, 2006, p. xviii). It seems that when encouraged to be honest about the pain one is brought face to face with the motivation for concealing it in the first place, i.e. one’s sociocultural programming. This reaction is similar to when someone who is healing from trauma gets triggered (Levine, 2008, chapter 2). Confronted with the sum of all the risk associated with being in a committed relationship and existing in this world as an “incomplete woman”, one’s belonging in this world is threatened. Considering this, it makes sense that the thought of revealing one’s pain is associated with danger and that enduring excruciating yet familiar pain for a few minutes may seem like the best option. The prospect of being honest and interrupting intercourse may also seem more challenging if one has no idea for what to do next.

According to neuroscience, bodily experiences like freezing, not being able to think clearly or form words, form the foundation for emotional states that “shape the quality of our decision-making efforts and the solutions we create to deal with particular dilemmas” (van der Kolk, 2006, p. xviii). Van der Kolk points out that emotions serve as guides for action, and that the goal of negative emotions, like in the case of these women, - fear, overwhelm and shame, is to help the organism get out of harm’s way. In this case “harm” would be the loss of one’s partner’s love and affection, perhaps even the loss of one’s place and belonging in society. In such a situation, it would make sense that the impelled action is to conceal one’s pain.

The seemingly irrational behaviour, to say “no” when asked if one is in pain, may be an example of what trauma experts explain, which is that trauma lives in the body as a latent response to stimuli that would otherwise not cause the person to feel overwhelmed or helpless in certain situations (Levine, 2008, chapter 3; van der Kolk, 2006, pp. xix-xx). In a trauma perspective, the frustration at not being able to voice one's pain can make sense as the causes of trauma responses are often not obvious to the person him or herself (Ibid). Without a historical context to understand the somatic and motoric carryover from the past, the emotions of traumatized people appear out of place and their actions bizarre (van der Kolk, 2006, p. xviii). Unidentified traumatization may thus continue to shape a person's behaviour and dealing with certain situations because they trigger the same response over and over again, also called "compulsion to repeat" (Levine, 2008, p. 19).

The experience of being overwhelmed and paralyzed fuels negative cognitive associations to the trauma and prevent effective information processing on cognitive, emotional and sensorimotor levels (Ogden et al., 2006, chapter 1). Trauma-related cognitive distortions feel confirmed again and again: "The world is dangerous. I will never be safe" (Ibid), or as one of the participants put it: "*no, there's no point, we should just stop everything. We can never have sex again.*"

The fear-avoidance model postulates that several psycho-social factors (pain-related fears, catastrophizing and hypervigilance) are leading to two oppositional strategies of confrontation (having sex) and avoidance (Desrochers et al., 2010, p.107). However, if we consider it so simply that one behavior leads to improvement and the other not (Ibid), we may fail to discover and help women who are trapped in the destructive, "confrontational" behavior of suffering through painful intercourse because they feel like they don't have a choice.

5.7 CREATING A SAFE ENVIRONMENT – AND POTENTIAL FOR HEALING

Finding it hard to "*just say no*" to painful sex may be connected to difficulty in making others understand the pain, especially one's partner. Participants in the qualitative study of Amy Braksmajer described feeling relief when told by the doctor not to have sex if it hurts (2018, p. 424). Considering these findings parallel to the present study, the desire to make the partner understand the pain may be because it makes it easier to voice one's pain during sexual intimacy. When insecure whether one's authentic Self is worthy of acceptance and love, one may see one's need to interrupt painful activity as invalid. Being overwhelmed by one's own "inner demons", it seems difficult to handle a partner's insecurity and confusion. Conversely, when he understands the negative impact of the pain, she has reason to trust him to be of support when she faces it.

In an overwhelming situation, the focus will be on the surroundings as one's entire system is wired for vigilance, which makes it difficult to access resources for coping and processing (Levine, 2008, pp. 25-30; van der Kolk, 2006, pp. xxi-xxii). In a safe environment it may be easier to turn the focus toward the experience and access one's resources for coping and processing, noticing feelings and needs and understand one's responses (Ibid). According to Engelsrud, going from holding the breath to allowing it to flow enables this mind-body connection as the sense of the weight of the body is reestablished and one can become aware of tension in muscles, discomfort and pain (Engelsrud, 2006, p. 63). As we have seen, becoming aware of what triggers one's default response also makes it possible to explore what makes one feel safe. It seemed that participants had discovered that a safe environment enabled them to maintain access to these coping resources through triggering experiences and transform their responses to the perceived danger. It seems that forming a safe environment began with finding a partner who is willing and capable of learning how to support her when she loses control in situations that trigger overwhelm.

The time and effort of teaching the partner seems to add to the vulnerability that these women cope with. Van der Kolk explains how when we get overwhelmed by triggers that bring up painful past experiences that have not been processed and integrated as memories, the part of our brain that keeps track of past and present shuts down. We react as if we are in that past experience right now (van der Kolk, 2006, p. xx). Considering this, there seems to be a contradiction in guiding a partner and observing his ability to be supportive while simultaneously being in a vulnerable state where overwhelm can be triggered. Daring to expose oneself to the things that trigger overwhelm in the presence of a partner while still discovering how to transform one's responses seem like a courageous and difficult endeavor. After all, some of the things that have triggered overwhelm for these women relate to how they have been received by previous partners.

The women seem to trust their body to tell them whether they could be safe enough with their partner through experiencing his touch. If we consider the therapeutic effect of being touched by confident and caring hands that also sense what and who they are touching (Bunkan, 2014, pp. 32-33), it makes sense that the experience of being touched is an important source of information about the partner's consideration and interest in one's wellbeing. Gretland writes that the coherence we experience when we figure out a way to move together, creates trust and safety in relationships as we discover coherence in the way we move, and in our intentions (Gretland, 2007, pp. 30-31).

Trusting the other to be willing and able to hold space for one's emotions seems to be another key ingredient to feeling safe, which is well a well-known requirement for patient-therapist relationships to facilitate positive change and increased awareness (Bunkan, 2014, pp. 272-273). Being held space for, participants seem capable of exploring areas of their sensual-sexual landscape where they know they may come in touch with painful triggers. Although giving up some control by becoming vulnerable, it seems they actively create opportunities for gaining control in situations that they associate with having no control at all. Seeing that the partner receives one's vulnerability and openness with appreciation and respect seems to boost confidence and strengthen the Self.

5.8 TRANSFORMING PAIN RESPONSE DURING SEX

It seems that when the pain is understood as a symptom of harmless physical disease, one can train oneself to relax with mild pain. This ability seems connected to having a certain level of control in terms of trusting oneself as capable of stopping the activity if it becomes too painful. Perhaps the relaxation that comes with having control reverses pain-exacerbating factors like pelvic floor muscle tension and hypervigilance, thereby making it easier to notice pleasure? Conversely, when experiencing the pain as a warning that something was wrong, a signal that should be respected, trying to ignore or overcome the impulse to protect oneself seemed to be experienced as a form of self-violation. Seen from the perspective of Dr. Rosenberg, instead the pain becomes an ally, guiding her to awareness that something about the situation is in conflict with her needs (Rosenberg, 2003, chapter 4).

For women who experience their pain as an ally, relating to it during intercourse meant confronting the belief that it made them defect and not worthy of love. Needs-based psychology may help in understanding why working out a way to change this was hard: "It takes tremendous energy and awareness to recognize the destructive cultural conditioning that can lead to such perceived threats, and to transform it into thoughts and behaviours that are of value and of service to life" (Rosenberg, 2003, p.171). It requires a skill for identifying needs and capability to get in touch with oneself in the moment (Ibid). However, as previously discussed, overwhelming experiences make us loose connection to ourselves, our bodies and the people around us (Levine, 2008, p. 9). When someone is traumatized by causes that are less obvious than for example rape or severe sexual abuse, it may be even harder to recognize that this process of disconnection is occurring, and its relationship to the perceived threat (Ibid).

Having trained herself to suppress and override her feelings and bodily sensations as a means to avoid rejection, transitioning to relating to them as a guidance system may be difficult in itself. These women have been able to discover *how to* go about this process of transformation by using these resources, most of them without the guidance or support of someone outside the relationship. Orientating toward the pain as an ally seems essential to this approach, as it improves one's ability to relax with it. Rather than being dominated by fear of pain there seems to be a growing curiosity toward it; what is my pain telling me?

Changing one's response to pain during sexual intimacy seemed to begin with facing the self-blame at not being able to be honest about it and admitting this to the partner. Daring to trust another and reveal what one has been hiding out of shame allows one to present one's authentic Self (Farstad, 2016, p. 166). Whether the next moment brings re-traumatization or healing depends on the way her partner receives her. One can imagine that with a supporting partner, she can empathize and mourn the part of herself which had assumed the punishing voice of shame as a way to prevent her from showing her authenticity and risk being judged.

It seems that in letting go of some control, intimacy can deepen and aide the sense of disconnection and loneliness as the Self that is seen by the other expresses her authentic experience. Being given space to gather oneself, it seems one can reorient in the present moment and arrive at a place where it is possible to form words (Ogden et al., 2006, chapter 9; Farstad, 2016, chapter 4).

Ability to communicate verbally about one's experience and one's needs in the moment seems to bring a new sense of having control. Words give name to experiences that have previously been overpowering and incontrollable, without name. When we are able to articulate our experience in verbal language, there is a processing that occurs which also allows us to form a new relationship to that experience (Bunkan, 2014, p. 272; Gretland, 2007, pp. 184-188). One can develop the power to face and change pain experiences that have been threatening and incontrollable and identify the Self with that ability and agency.

When in a safe relational environment, one can begin to explore alternative solutions to run into hiding, like saying "stop", or "pause". It becomes possible to begin facing the pain and heal the trauma response when overwhelm kicks in, provided one continues to be held safely in this relational space (Levine, 2008, chapter 4; Gretland, 2007, pp. 198-204). The partner's calm presence may act as a form of grounding in the present moment which makes it easier to tolerate the arousal of the negative situation, and to return to relaxation afterwards (Ibid).

When trusting the partner’s ability to do this, she is able to pause and breathe when facing the pain and notice her reaction to it, even during penetration. Negative anticipation and muscle tension can release, and the breath become slower and deeper (Levine, 2008, chapter 4). Can it be that when one is feeling safe and loved, and not attributing the pain to the partner’s ignorance or selfish gain, that the body is capable of accepting him and not tense up even more? It seems the pain can be dealt with without having to disengage physically from intercourse as long as one trusts the partner completely; That by relaxing, one can discover that in moving slowly and breathing deeply one can attain control in an otherwise overwhelming situation, and that the pain can release with that. Perhaps the freedom in being authentic about one’s experience changes the pain experience in itself?

Considering the connection between overwhelm and losing access to one’s coping resources, one can understand why transforming one’s response to pain during sexual intimacy is hard work. However, seeing that women who embrace their own responsibility for the pain are capable of this transformation can give clues for understanding the findings of other studies that women with this understanding of their pain adopt healthier behaviours and feel that PVD is less threatening to their relationship (Jodoin et al., 2011, p. 93).

5.9 DEEPENING INTIMACY AND DISCOVERING PLEASURE

In doing the hard work of transforming something negative, these women seem to have discovered their capacity to explore new “sexual territory” and find pleasure and desire. The strong emotion that arises when one discovers that one’s desire suddenly (re)appears during this type of exploration may be understood in several ways. Psychosocially, it may be understood as the relief of being “normal”, based on the idea that “everyone else” has access to this state of being. Phenomenologically, it may be understood as becoming more alive; As feeling an aliveness and zest for life awakening from within, and the joy that comes with that.

Knowing what one wants and knowing that one can make it happen gives rise to sexual subjectivity and -agency (Tolman, 2012, p. 750). Gaining experiences that prove one’s ability to turn a negative situation into a positive one seems to support this development even more. What if these women were encouraged to explore other sensations than pain in the first place? Could the work of transforming pain responses be less hard?

As the physical processes that are activated during sexual arousal are similar to those when we are in danger, sexual arousal can trigger fear (Ogden, 2006, chapter 2). Can this make sexual exploration particularly challenging for women with PVD? Perhaps these women's experiences show that one can become more tolerant of arousal and discern "negative" and "positive" arousal by training oneself to focus on sensations and feelings during sexual exploration, as well as practicing awareness of what is going on in the moment? There is a growing body of research into the use of mindfulness techniques for women who suffer from PVD which suggests this connection (Craven et al., 2016, pp. 531-535;).

Realizing that penetration is experienced in a different way when one is *longing* for it, the motivation to engage in it shifts from something one should be doing in order to be a "true woman" to something that can fulfill one's need for pleasure in a moment when one's entire being is desiring it. Realize that one can have no hard feelings toward the partner in order to feel this longing, there seems to be a shift in how the vulva and body are valued. It is as if intercourse must happen in a way that is honoring of one's Self and one's body as worthy of experiences that feel nothing but right.

The present finding may contribute valuable insight into the findings of other researchers; that greater relationship intimacy and sexual intimacy is associated with greater sexual satisfaction and sexual function, as well as higher confidence that one can cope despite the pain (Bois et al., 2013, p. 2033; Craven et al., 2016, p. 531). Having deepened emotional intimacy, it seems one feels safe enough to concentrate on receiving touch without having to give anything back. In relaxing while receiving touch, one can discover sensations and feelings and learn to communicate them. When not supposed to be "giving" anything back in the moment, there is an opportunity to experience a sexual situation which is centred around one's own desires and needs as opposed to the male-centred focus of heteronormativity. One may think that experiencing the partner as engaged in the sexual activity for the sake of her pleasure feeds her sense of entitlement to pleasure as it has been described by Tolman (2012, p. 750).

Having learned that psycho-emotional disconnection from themselves and from their partner during sexual intimacy can cause painful situations and trigger fear of pain, these women seem to maintain connection through eye-contact and skin contact as a way to stay safe throughout sexual intimacy. Using touch especially seems to work as a strategy to communicate non-verbally with the partner, and as a way to compensate for the inability to speak if overwhelm is triggered. This can be understood as a way of being self-responsible in accordance with one's sexual ethics (Beres & Farvid, 2010, pp. 378-379). Seeking safety by connecting more intimately with the partner, one is (re-)awakening and mobilizing one's inherent ability to form attachment with oneself and one's partner, make new decisions based in new experiences and newfound awareness of choice, as well as acquire new behavioural structures (Merleau-Ponty, 1994, p. 118). By dealing directly with both shame and pleasure together, they form a relational space where belonging is possible without having to change or conceal anything about oneself. If we consider the experience of being penetrated dependent on a readiness and desire of both body and mind, can the knowing that one is accepted and loved be just as important in making penetration pleasurable as muscle relaxation?

Through this orientation toward sexual exploration it seems the sexual concepts and sexual Self of these women are formed by what is conceptualized in sociology and psychology as an *embodied desire,* described as "sexual and pleasurable feelings in and of the body that constitute a form of knowledge about the self, one's relationships and one's cultural and social worlds" (Tolman, 2012, p. 749). It would seem that having an embodied desire for sexual intimacy goes hand in hand with accepting oneself as different and an improved coping with pain for these women.

5.10 LIMITATIONS

Processing the wide spectrum of data has taken much more time than anticipated. Gathering a wide range of theory was required post analysis, which has made it challenging to discuss each finding in depth. If the research question had been adjusted to the findings that stand out as the most unique, more time could have been spent discussing the results. A revised question could have been, "How do women with PVD cope with the challenge of voicing their pain during situations of partner intimacy?".

6 CONCLUSION

This study suggests a connection between view of pain and sexuality and choice of coping strategies within this sample of 9 women with PVD. The participants' felt pressure and tendency to endure painful intercourse is reflected in other studies, while few receive help in dealing with this outside the relationship. In the discussion it is hypothesized that this behaviour may be traumatizing in itself. The results suggest that dualistic health discourse and heteronormativity are important contextual factors for the development of this behaviour:

That combined, they create a negative environment for women's ability to trust themselves and their own experience, in turn causing them to separate from their inner guidance for healthy sexual decision-making.

The study further hypothesizes a connection between this difficulty and that women move either way from or toward partner intimacy and self-acceptance to achieve control. In close collaboration with their partners, some women in the sample are capable of mobilizing resources within themselves and the relationship and transform the compulsion to endure painful intercourse in silence. In the process they are healing psychosocial factors that contribute to the severity and duration of pain such as fear of pain, pain catastrophizing and shame. Developing sexual subjectivity and agency in this way seems to improve sexual functioning and lessen the pressure of socio-cultural norms.

Further research is needed to understand better why it is so difficult to change this pattern and how health care personnel can support women and their partners in mobilizing resources and skills necessary to make this transformation. Based on previous qualitative research there is reason to believe that the perceived duty to fulfil intercourse leads to both fear-avoidant behaviour and compulsion to endure painful sex in silence. It seems important to research this connection further, as therapists may fail to identify potential pain-exacerbating behaviours in PVD women who are sexually active.

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8 APPENDIXES

8.1 APPENDIX 1

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region: REK sør-øst

Saksbehandler: Ingrid Dønåsen

Telefon: 22845523

Vår dato: Vår referanse: 25.01.2018 2017/1835 REK sør-øst B

Deres dato: Deres referanse: 19.01.2018

Vår referanse må oppgis ved alle henvendelser

Marthe Schneider
Høgskolen i Oslo og Akershus

2017/1835 Hvilke faktorer har vært med å forme forholdet til kropp og seksualitet hos kvinner med vestibulodyni?

Forskningsansvarlig: Høgskolen i Oslo og Akershus **Prosjektleder:** Marthe Schneider

Vi viser til tilbakemelding mottatt 19.01.2018. Tilbakemeldingen er behandlet av leder for REK sør-øst B på delegert fullmakt.

Prosjektleders prosjektbeskrivelse

Forskningsprosjektet har til hensikt å skaffe til veie informasjon om hvilke faktorer som preger pasientgruppens forhold til egen seksualitet, utover de smertene de har, og utover eventuell tidligere erfaring med seksuelle overgrep. Slik informasjon kan bidra til å danne grunnlag for videre utvikling av forebyggende tiltak, og for behandling av den aktuelle smertetilstanden. Man ønsker å innhente denne informasjonen ved å intervjue kvinner med den aktuelle plagen. Intervjuene vil være semi-strukturerte, for å hente frem den subjektive opplevelsen hos kvinnene. Forskningsprosjektet vil ha en fenomenologisk tilnærming, og man tar sikte på å bruke systematisk tekstkondensering for å analysere materialet slik at det gis rom for utvikling av nye begreper dersom dette viser seg aktuelt.

Saksgang

Komiteen behandlet prosjektet første gang i møtet 25.10.2017. Jamfør brev datert 24.11.2017 utsatte komiteen å fatte vedtak i saken. Komiteen ba om prosjektleder om en nærmere redegjørelse for beredskapen i prosjektet, samt revisjon av informasjonsskrivet slik at det er tydelig hvor deltakerne kan henvende seg ved behov for oppfølging av kompetent helsepersonell.

Ved en feil ble vedtaket ikke sendt på e-post til prosjektleder før 19.01.2018. Prosjektleders tilbakemelding ble mottatt samme dag. Tilbakemeldingen er behandlet av komiteens leder på fullmakt.

Prosjektleders tilbakemelding

Prosjektleder har i sin tilbakemelding redegjort for beredskapen i prosjektet:

«Alle deltakere vil bli orientert om muligheten for oppfølging av kompetent helsepersonell i etterkant av intervju. De vil bli oppfordret til å ta kontakt med prosjekteder Marthe Schneider dersom de trenger støtte og hjelp til å bearbeide eventuelle ting som har kommet opp i forbindelse med intervjuet. Marthe Schneider har avtale med en psykolog som vil stå til disposisjon for de som trenger slik oppfølging.»

Informasjonsskrivet er oppdatert med informasjon om muligheten for oppfølging av psykolog ved behov for hjelp til å håndtere eventuelle reaksjoner etter intervjuet.

Komiteens vurdering

Komiteen finner at prosjektleder har svart tilfredsstillende på dens spørsmål og kommentarer. Komiteen har ingen ytterligere innvendinger til at prosjektet gjennomføres slik det nå foreligger.

Oppgitt sluttdato for prosjektet er 15.05.2018. Komiteen setter imidlertid prosjektslutt til 31.12.2018, slik at det er tilstrekkelig tid til å gjennomføre prosjektet. Ved behov for ytterligere utsettelse må dette søkes REK via skjema for prosjektendring.

Vedtak

Med hjemmel i helseforskningsloven § 9 jf. 33 godkjenner komiteen at prosjektet gjennomføres.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknad og protokoll, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 31.12.2018. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 31.12.2023. Opplysningene skal lagres avidentifisert, dvs. atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder "*Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren*" .

Sluttmelding og søknad om prosjektendring

Prosjektleder skal sende sluttmelding til REK sør-øst på eget skjema, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK sør-øst dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst B. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst B, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Ragnhild Emblem professor, dr. med. leder REK sør-øst B

Kopi til: postmottak@hioa.no

Ingrid Dønåsen Rådgiver

8.2 APPENDIX 2

Forespørsel om hjelp til å rekruttere deltakere til forskningsprosjekt

Problemstilling:

Hva forteller kvinner med provosert vestibulodyni om sitt forhold til seksualitet?

Dette er et spørsmål til deg om å bidra til å rekruttere deltakere til dette forskningsprosjektet, hvis formål er å bedre forutsetningene for god behandling av kvinner med provosert vestibulodyni (PVD). Undertegnende ønsker å intervjue 6 kvinner med den aktuelle diagnosen, om deres forhold til kropp og seksualitet. Undertegnende er ansvarlig for prosjektet, under veiledning av Gro Killi Haugstad ved Høyskolen i Oslo og Akershus.

Hva innebærer PROSJEKTET?

Prosjektet dreier seg om å intervjue 5-6 kvinner med PVD om deres forhold til kropp og seksualitet. Intervju-samtalen vil vare inntil ca 1,5 time og det vil bli gjort lydopptak.

Deltakerne vil bli spurt om sitt forhold til kropp og til seksualitet, og om hva som kan ha hatt formet det, utover de smertene de har.

Kriterier for deltakelse

Aktuelle deltakere er kvinner med PVD, eldre enn 18 og yngre enn 40. Deltakere må være i gang med behandling eller ha gjennomført behandling hos kompetent fysioterapeut eller tilsvarende.

Eksklusjonskriterier

Kvinners som har smertetilstander i andre deler av kroppen i tillegg til PVD er ekskludert fra studien.

Mulige fordeler og ulemper

Intervjuprosessen kan virke bevisstgjørende om tema som deltakeren kan ha nytte av i behandlingsøyemed, selv om denne samtalen ikke har noe behandlingsformål.

Deltakere vil når som helst under intervjuet få mulighet til å ta pause eller ombestemme seg angående deltakelse.

Deltakelse kan når som helst trekke sitt samtykke etter at dette er gitt.

Rekruttering

Aktuelle deltakere som ønsker å delta undertegner samtykkeerklæringen hos deg. Deltakerne vil deretter bli kontaktet av undertegnende. Når en deltaker er rekruttert trenger jeg beskjed om dette slik at jeg kan hente samtykkeerklæringen og få deltakerens navn, telefonnummer og epostadresse.

Det er bare å ta kontakt med meg dersom du lurer på noe.

Vennlig hilsen,

Marthe Schneider

Telefon: 95281267

E-post: marthe.schneider@volvat.no.

8.3 APPENDIX 3

Forespørsel om deltakelse i forskningsprosjekt

Hvilke faktorer har vært med å forme forholdet til kropp og seksualitet hos kvinner med vestibulodyni?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å bedre forutsetningene for god behandling av provosert vestibulodyni (PVD). Du er invitert til å delta gjennom en samtale om dette tema fordi du har den aktuelle diagnosen og din opplevelse er en helt unik og verdifull kilde til informasjon. Det er Marthe Schneider som er ansvarlig for prosjektet, og hun er under veiledning av Gro Killi Haugstad ved Høyskolen i Oslo og Akershus.

Hva innebærer PROSJEKTET?

Prosjektet dreier seg om å intervjue kvinner med vestibulodyni om deres forhold til seksualitet. Intervju-samtalen vil vare inntil ca 1,5 time og det vil bli gjort lydopptak.

I prosjektet vil vi innhente og registrere opplysninger om deg. Vi vil spørre deg om ditt forhold til seksualitet, og om hvordan smertene og andre ulike tema har hatt betydning for utformingen av ditt forhold til seksualitet.

Mulige fordeler og ulemper

Deltakelse i dette prosjektet er adskilt fra den behandlingen du får hos din fysioterapeut, men det kan være at du blir bevisst ting i løpet av intervjuet som det kan være nyttig for deg å snakke med fysioterapeuten din om.

Dersom du trenger å ta en pause i løpet av intervjuet, er dette helt i orden. Du kan når som helst underveis i samtalen be om at vi avbryter intervjuet dersom du ombestemmer deg i forhold til deltakelse. Da vil lydopptaket av samtalen bli slettet med en gang.

Dersom du i etterkant av intervjuet trenger hjelp til å håndtere dine reaksjoner vennligst ta kontakt med Marthe Schneider på 95281267, så setter hun deg i kontakt med psykolog slik at du får time raskt.

Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre behandling. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte Marthe Schneider på 95281267 eller på epost marthe.schneider@volvat.no.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste som kun Marthe Schneider har tilgang til.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest åtte år etter prosjektslutt.

OppfølgingsPROSJEKT

Det kan bli aktuelt med et oppfølgingsprosjekt. I så fall kan du bli kontaktet igjen på et senere tidspunkt.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

Jeg er villig til å delta i prosjektet

Sted og dato Deltakers signatur

Deltakers navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet.

Sted og dato Signatur

Rolle i prosjektet

8.4 APPENDIX 4

Intervjuguide

Studie: Master i Psykisk Helsearbeid

Kandidat: Marthe Schneider

Veileder: Gro Killi Haugstad

Problemstilling: Hva forteller kvinner med vestibulodyni om sitt forhold til seksualitet?

<u>Innledende spm:</u>

Alder

Varighet smerter

Barn

Graviditet

Partner

- Hvordan opplever du smertene?
    - Hvor og hvordan kjennes de?
    - Varighet, kommer og går?
    - Hender det at du glemmer smertene eller ikke kjenner dem?
    - Fikk du smerter ved debut eller senere?
    - Har du gått hos fysioterapeut eller annen behandling for dette tidligere?

3 hovedspørsmål:

1. **Hvordan er det å leve med VD?**

- Hemmer det deg i hverdagen (i det du liker å gjøre/må gjøre)?
- Hender det at du ikke kjenner det i det hele tatt?
- Når du kjenner smerten, hva føler du da? (katastrofetanker?)

- Hva gjør du når du føler det? / Hva gjør den følelsen med deg?
- Har det hatt noen betydning for hvordan du har det med kjæresten/partner/dating?

2. Hva har det å si for forholdet ditt til kroppen og seksualiteten din?

Aktuelle oppfølgingsspørsmål:

KROPP

- Hvordan opplever du kroppen din etter du fikk VD?
- Hva med når du dusjer, kan det være behagelig?
- Er det ting du kunne glede deg over før du fikk VD som er annerledes nå?
    - Fritidsinteresser (dans, ridning, sykling, reising)?
    - Klær du liker å ha på?
    - Seksuell aktivitet?

SEKSUALITET:

- Er det andre former for nærhet (enn samleie) som du kan ha det godt med sammen med kjæresten din?
- (Hvis ikke): Hvorfor blir du redd/kan du ikke nyte det?
- Hva er dine forventninger til sex og til evt gleden ved det?
- Er det noe ved nærhet og sex som du synes du må gjøre?
- (Dersom smerter kom etter debut): Var det annerledes å ha sex før du fikk smerter?
    - Libido, nytelse, forventning, uttrykk for lyst, grensesetting.
- Er det noe ved sex som du synes du kan ha det godt med når du er alene?
- Når du får vondt under sex, hva gjør du da?
- Hvordan opplever du kroppen din i intime situasjoner (når du er naken sammen med kjæresten, han gir utrykk for lyst, når du selv har lyst?)

    - Hvordan kjennes pusten?
    - Er du avslappet eller kjenner du deg anspent?
- Kan du fortelle om en seksuell opplevelse som du husker spesielt godt?
- Hva opplever du at kjæresten din føler om at dere ikke kan ha sex (uten at det gjør vondt for deg)?
- Hva tenker du om din partners seksualitet og lystfølelse?
- Har du bekymringer i forhold til parforhold og fremtid? Barn?

3. Er det andre ting enn VD som har påvirket forholdet ditt til kroppen og seksualiteten din?

Aktuelle oppfølgingsspørsmål:

- Har det vært noe da du var barn som har hatt betydning for deg og seksualiteten din?
    - Var det greit å se seg i speilet, tørke seg på do osv...
    - Hva med i gymtimen?
    - Brukte du tampong da du fikk menstruasjon?
- Er det andre ting som du har opplevd som kan ha hatt betydning for hvordan du har det med kroppen og seksualiteten din?
    - Holdninger blant venner, kjæreste, foreldre
    - Informasjon (seksualundervisning, media, pornografi)
    - Puberteten, menstruasjon, hygiene og prevensjon?
    - Undersøkelse hos gynekolog eller fysioterapeut?
    - Andre opplevelser, positive eller negative?
- Er det noe som du tenker på som jeg ikke har spurt om / som du ikke har fått fortalt / som kan fylle inn?

8.5 APPENDIX 5

Intervjuguide, justert.

Studie: Master i Psykisk Helsearbeid

Kandidat: Marthe Schneider

Veileder: Gro Killi Haugstad

Problemstilling: Hva forteller kvinner med vestibulodyni om sitt forhold til seksualitet?

Innledende spm:

Alder:

Varighet:

Barn:

Graviditet:

Partner:

Har du andre helserelaterte problemer enn PVD?

Hvordan er det å leve med PVD?

- Fikk du det sammen med debut eller etter?

Hvordan og når fant du ut av at du hadde det?

Hvordan har det vært å snakke med andre om det?

- Helsepersonell?
- Foreldre?
- Kjæreste?
- Venner?

Hvordan har du det i kroppen? Hva kjenner du? Flere ting enn smerter?

- Hvordan ser du på kroppen din?
- Underlivet ditt?
- Å være naken alene
- Å være naken sammen med noen
- I forhold til typer klær
- Hvordan kjennes kroppen når du er sammen med kjæresten din?

Hva legger du i ordet sex? Hva betyr sex for deg?

- Hva er ditt forhold til å ha sex alene?
- Hva er ditt forhold til partner sex

Hvordan synes du det er å prate om det her og nå?

- Og prate om det med andre?

Er det noe du vil ha? Hvorfor?

- Unngår du sex eller oppsøker du det?
- Hva er dine forventninger til sex? (glede, nytelse, nærhet)

Hvis du fikk smerter etter debut, hvordan var det å ha sex før?

Hvordan synes du det er med fysisk kontakt (klemming, kos etc)?

Hvordan har det vært for deg å finne kjæreste som tar deg som du er?

Hvordan er kjæresten?

- Åpen, forståelsesfull, nysgjerrig, hjelpsom?
- Synes synd på deg?
- Forsiktig, tilbakeholdende?
- Passer tissen hans til deg?

Hvordan snakker du med kjæresten om det?

Hvordan forholder dere dere til det som par?

Hvordan løser du/dere det når samleie gjør vondt? Eller hva gjør du for å unngå smerten?

- Sier du ifra til kjæresten?
- Stopper du? Gjør du noe annet?
- Har du utforsket sammen med noen eller alene?
- Hva får du ut av sex?
- Hvorfor har du sex?

Hvis smertene kommer og går, vet du hva som gjør at det blir bedre eller verre?

- Hva med pust, stillinger, forberedelser, tidsbruk, hjemmebane/bortebane?

Hender det at du stopper deg selv fra å være nær den du er glad i?

Hva hindrer deg (i å kysse, klemme, ha sex)?

Hva tenker du om fremtida?

- Bli bedre?
- Samliv?
- Barn?

Er det noe seksuelt som du skulle ønske du kunne gjort dersom du ikke hadde hatt smerter?

- Snakke om sex med andre?
- Seksuelle aktiviteter?
- Utforske?
- Ha one night stand?
- Uttrykke deg blant andre (bevegelser, klær?)

Har du hatt både gode og vonde seksuelle erfaringer tidligere?

- Kan du si noe om hva som gjør det bra?
- Dårlig?

Har det å leve med PVD lært deg noe om seksualiteten din?

Hvis hjelpen kunne vært bedre, hva burde vært annerledes?

8.6 APPENDIX 6

First literature search

The initial search was made on October 16th, 2017.

The databases MedLine and PsychInfo were searched. The search strategy in both databases was based on the following search terms:

Vestibulodynia, vulvodynia, central sensitization, sexuality, sexual dysfunction, psychological distress.

For each search, the search terms were adapted to the keywords and mesh terms of each database. Below is a copy of the searches which show how search terms were combined. The searches yielded 48 and 50 results. Of these, 18 articles were selected for the study.

Studies about the following topics were excluded:

- Other diagnoses than PVD, Vulvodynia or dyspareunia (Clitoral Pain, cancer, persistent genital arousal and restless genitalia, etc.)
- Surgical treatment of PVD
- Biological factors and local interventions for the pelvic floor musculature.
- Evaluation of the use of questionnaires
- Evaluation of treatment interventions
- Study of PVD prevalence among women who seek help at vulvovaginal specialist clinics
- Prevalence studies from 2011 or older
- Studies in other languages than English and Norwegian
- Litterature reviews from before 2010

MedLine: 48 articles

1. vestibulodynia.mp. or Vulvodynia/
2. central sensitization.mp. or exp Central Nervous System Sensitization/

3. Sexuality/

4. Sexual Dysfunctions, Psychological distress/ or Sexual Dysfunction, Physiological/

5. 1 or 2

6. 3 or 4

7. 5 and 6

8. limit 7 to yr="2007 -Current"

PsychINFO: 50 articles

1. Vulvodynia.mp.

2. exp SEXUALITY/

3. exp Dyspareunia/ or vestibulodynia.mp.

4. exp Female Sexual Dysfunction/

5. exp Sensitization/ or central sensitization.mp.

6. 1 or 3 or 5

7. 2 or 4

8. 6 and 7

8.7 APPENDIX 7

Second literature search

The second literature search was made on June 29th, 2018, when the last interview was done. The databases MedLine and PsychInfo were searched. The search strategy in both databases was based on the following search terms:

Dyspareunia, provoked vestibulodynia, sexual self-schema, consent, sexual agency.

For each search, the search terms were adapted to the keywords and mesh terms of each database. Both databases were searched using the procedure shown below. The searches yielded 25 results combined. Of these, only 11 articles were relevant for the study.

Search procedure:

1. Dyspareunia
2. provoked vestibulodynia
3. 1 or 2
4. sexual -self schema
5. 3 and 4
6. consent
7. 5 and 6
8. sexual agency
9. 7 and 8