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Assessing the impact of chronic pelvic pain in women: A mixed methods study

by

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Abstract

Chronic pelvic pain (CPP) is multifaceted in nature and is related to a number of disorders including endometriosis, chronic pelvic inflammatory infection, and irritable bowel syndrome (IBS). This thesis aimed to explore the experiences of women with CPP and provide a thorough review of research examining different treatments and interventions for women experiencing sexual pain. In addition, this thesis aimed to develop a new measure that assesses the impact of CPP on women's lives.

Study 1: A systematic review of the literature that investigated which treatments for female sexual pain have been evaluated in clinical studies and the clinical effectiveness of these treatments.

Study 2: A qualitative study that explored women's experiences of CPP in terms of their ability to cope with the pain and their perceptions of how the pain had impacted their ability to work, socialise, engage in hobbies, exercise, and personal relationships. This was achieved by conducting in-depth interviews with 25 women with CPP.

Study 3: A think-aloud study with 10 women with CPP that aimed to pilot and develop a new questionnaire that assesses the impact of CPP: The Impact of Female Chronic Pelvic Pain questionnaire (IF-CPPQ). The development of the questionnaire was informed by findings from Study 2.

Study 4: A questionnaire study that assessed the validity, reliability, and factor structure of the IF-CPPQ. This was achieved using exploratory and confirmatory factor analysis, Cronbach's alpha, and Pearson correlations with related validated measures.

Despite the number of interventions reported as effective for women with sexual pain, only a minority of women report complete relief of their pain. Less invasive treatments should be considered first by women before undergoing surgery such as physical and psychological therapies. Study 2 highlighted the diverse impact of the pain in virtually every aspect of women's lives. Thus, it is important that health professionals acknowledge how women are affected by their CPP emotionally and psychologically. Study 4 demonstrated that the IF-CPPQ is a psychometrically sound measure. Such a measure is lacking in CPP research and would be a useful measure for understanding how women are affected by CPP.

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- Al-Abbadey, M (2016, March). *The development of an online questionnaire that assesses the impact of female chronic pelvic pain: A think aloud study*. Talk presented at a CAHP seminar at the University of Southampton, Southampton.

Declaration of authorship

I, Miznah Al-Abbaday declare that the thesis entitled '**Assessing the impact of chronic pelvic pain in women: A mixed methods study**' and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

Signed:

Date:.....

I also declare that the thesis entitled '**Chronic pelvic pain: What are the everyday and sexual experiences of women with chronic pelvic pain and can they be reliably evaluated?**' if successful, will be made available electronically through the University of Southampton Research Repository from a date stipulated (subject to the law of copyright).

Signed:

Date:.....

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List of abbreviations

CBB	Cognitive-behavioural bibliotherapy
CBT	Cognitive behaviour therapy
CFA	Confirmatory factor analysis
CFI	Comparative Fit Index
CPP	Chronic pelvic pain
DSM	The Diagnostic and Statistical Manual of Mental Disorders
EAU	European Association of Urology
EFA	Exploratory factor analysis
EMG	Electromyographic biofeedback
GCBT	Group cognitive behavioural therapy
GPPPD	Genito-pelvic pain/penetration disorder
GRS	Graphic rating scale
HRQOL	Health-related quality of life
IBD	Inflammatory bowel disease
IBS	Irritable bowel syndrome
IC	Interstitial cystitis
ICD	International Classification of Diseases
ICSIPI	Interstitial Cystitis Symptom Index and Problem Index
IF-CPPQ	The Impact of Female Chronic Pelvic Pain Questionnaire
ISSVD	International Society for the Study of Vulvovaginal Disease
LUNA	Laparoscopic uterine nerve ablation
MRI	Magnetic resonance imaging
MVP	Multidisciplinary vulvodynia program
PAF	Principle axis factor analysis
PFD	Pelvic floor disorder

PFMs	Pelvic floor muscles
PFPT	Pelvic floor physical therapy
PROMs	Patient reported outcome measures
PUF	Pelvic Pain and Urgency/Frequency
PVD	Provoked vestibulodynia
RCT	Randomised controlled trial
RMSEA	Root mean square error of approximation
sEMG	Surface electromyography
SPT	Supportive psychotherapy
tDCS	Transcranial direct current stimulation
TENS	Transcutaneous electrical nerve stimulation
QOL	Quality of life
VAS	Visual analogue scale
VRS	Verbal rating scale
VV	Vulvar vestibulitis

Chapter 1: Thesis Introduction and Outline

Introduction

This thesis presents a new measure that aims to assess the impact of chronic pelvic pain (CPP) on the functioning and wellbeing of women. This chapter will first provide an introduction to CPP, explain current issues regarding diagnosis and treatment, highlight why more research is needed, and discuss what benefits a new measure would bring within this field. Sexual pain problems in women will also be discussed and introduced, and their relationship with CPP will be highlighted. The main aims and research questions will be presented and finally, the chapter ends with an outline of the thesis overall.

Chronic pelvic pain (CPP)

What is CPP?

CPP is the most common reason for referral to women's health services (Latthe, Latthe, Say, Gülmezoglu, & Khan, 2006a). It can be defined as persistent pain in structures related to the pelvis and is associated with negative cognitive, behavioural, sexual, and emotional consequences (Engeler et al., 2004). The estimated global prevalence of CPP varies between 2.1%-24%, depending on the quality of the studies and definitions used (Latthe et al., 2006a). There are differences in definitions of CPP in terms of duration (three vs four months) and pain episodes (chronic vs recurrent) (Latthe et al., 2006a). In addition, studies differ in their design (e.g. prospective vs retrospective), sampling adequacy (random vs convenience), response rates, and the use of validated standardised measures (Latthe et al., 2006). In the UK, annual direct treatment costs of CPP have been estimated at £158 million, with indirect costs at £24 million (Stones, Selfe, Fransman, & Horn, 2000).

CPP symptoms are varied, non-specific and related to a number of disorders, including endometriosis, chronic pelvic inflammatory infection, adhesions, irritable bowel syndrome (IBS), bladder pain syndrome, pelvic congestion syndrome, musculoskeletal conditions, and pelvic organ prolapse (Daniels & Khan, 2010; Latthe, Mignini, Gray, Hills, & Khan, 2006b). A brief description of common conditions associated with CPP is described in Table 1 (Appendix A). A diagnosis does not necessarily lead to treatment that resolves pain and for many women, on-going pelvic pain remains undiagnosed (Grace & MacBride-Stewart, 2008). Obtaining a diagnosis may be difficult because symptoms are very non-

specific. A potential cause for the pain may be found by investigating associated gynaecological, urogenital, or bowel symptoms (Cody & Ascher, 2000). The European Association of Urology (EAU) developed an algorithm for diagnosing and managing CPP, which supports the involvement of a multidisciplinary pain team and early intervention (Engeler et al., 2004). Diagnosis can be made through diagnostic laparoscopy or imaging techniques such as transvaginal ultrasound and magnetic resonance imaging (MRI) (Royal College of Obstetricians and Gynaecologists, 2005). Laparoscopy is the only method of confirming endometriosis and adhesions (Royal College of Obstetricians and Gynaecologists, 2005). However, because of the potential risks involved (Jansen, Kapiteyn, Trimbos-Kemper, Hermans, & Trimbos, 1997), laparoscopy has been proposed as a second line investigation to be undertaken after the failure of other therapeutic interventions (Royal College of Obstetricians and Gynaecologists, 2005). This can cause delays in diagnosis and lead women experiencing CPP to feel misunderstood by others (Ballard, Lowton, & Wright, 2006). Delays in a formal diagnosis have also led women with CPP to normalise their symptoms and to struggle to explain their inability to function ‘normally’ (Ballard et al., 2006).

The impact of CPP

Pain is a complex perceptual experience and is influenced by a number of psychosocial factors including emotions, environmental and social contexts, the meaning of pain to the individual, attitudes and beliefs, and biological factors (Turk & Okifuji, 2002). In turn, chronic pain will likely influence all aspects of an individual’s functioning. The biopsychosocial model provides a useful theoretical explanation of the relationship between CPP and QOL. The biopsychosocial model incorporates biological and mechanical processes as well as social and psychological factors that may either cause or prolong chronic pain (Turk & Okifuji, 2002). This contrasts with the unidimensional biomedical perspective, which focuses on physical, pathophysiological explanations for chronic pain (Turk & Okifuji, 2002). According to the biopsychosocial model, there is a dynamic and reciprocal relationship biological, psychological, and social variables that shape how individuals respond to pain. In the context of CPP, the model presumes physical changes or physical pathology that lead to nociceptive input to the brain (Turk & Okifuji, 2002). The signal is then interpreted and appraised by the individual, which involves identifying the type of pain experienced and attributing meaning to the pain (Turk & Okifuji, 2002). Such appraisals are influenced by beliefs developed by the individual over time (Turk & Okifuji, 2002). As a

consequence of the individual's beliefs and appraisal process, they may choose to either ignore or respond to the pain, which is in turn shaped by their environment and significant others (Turk & Okifuji, 2002).

Not surprisingly, the impact of CPP can be very negative for the individual woman and those close to them. In a study by Zondervan et al. (2001) women with CPP had poorer physical and mental health scores than normative UK population scores. Forty-two percent of women reported a restriction in activities due to their pelvic pain, with the most common restriction being lethargy, fatigue, and the inability to carry out activities without taking analgesics or rest. Other studies have found similar findings (Grace & Zondervan, 2006). Women with CPP are also more likely to experience sleep problems compared to those with no pelvic pain (Grace & Zondervan, 2006). As well as physical problems, women with CPP experience a significant amount of psychological distress (McGowan, Clark-Carter, & Pitts, 1998). Women with CPP are more likely than pain-free women to experience depression, anxiety, and score highly on neuroticism regardless of whether they do or do not have any obvious physical pathology (McGowan et al., 1998). The distress experienced by women with CPP is comparable to that reported by individuals with chronic pain of other aetiology such as chronic migraine headaches (Roth, Punch, & Bachman, 2011).

The effects of CPP can be investigated using qualitative research methods. Unlike quantitative methods, qualitative studies have the advantage of providing more detailed accounts of personal experiences and can capture the full range of descriptions women may attribute to pain (Grace & MacBride-Stewart, 2008). Price et al. (2006) investigated the attitudes that women with CPP have regarding their consultations at gynaecological clinics using a grounded theory approach. Twenty-six women between the ages of 18-70 were recruited. Women felt that they were not provided with personal care and did not feel understood or taken seriously. In addition, they felt that an adequate explanation of their symptoms and reassurance was not provided, which left them feeling worried or doubtful about their original diagnosis. Though the findings were insightful, it would have been beneficial to know what diagnoses the women were given as well as the number without a formal diagnosis because this would have given an indication of the nature of the CPP experienced by the women.

A large proportion of women stop seeking healthcare despite experiencing ongoing symptoms (McGowan, Luker, Creed, & Chew-Graham, 2007). McGowan et al. (2007) recruited 32 women with CPP between the ages of 21-50. Using a qualitative narrative approach, it was found that in the context of a medical consultation, women with CPP did not

feel their stories were heard or believed. Doctors' interpretations of their stories were not in alignment with the women's own stories and the way that women were informed about negative test results can also contribute to why some women may disengage from healthcare. Consistent with the findings of Price et al. (2006) not all the diagnoses given to patients were clearly specified. In the McGowan et al. (2007) study, the participants were required to submit written accounts of their experiences rather than report these during an interview. Although writing may have given the women more control over the research process with less influence from an interviewer by prioritising important aspects of their story, important non-verbal communication and more natural narratives/discourse may have been missed.

It may be that physicians' attitudes to the consultations contribute to treatment outcome. Selfe, Van Vugt, and Stones (1998) investigated attitudinal constructs about pelvic pain in women. A questionnaire assessing five attitudinal constructs was created based on focus group discussions with gynaecologists, general practitioners (GPs) and patients. The questionnaire was sent to 179 gynaecologists. The advantage of the use of focus groups is that it allowed the research to tap into the women's collective experience that is reliant on group interactions. Younger gynaecologists and those that stated their ethnic origin as Caucasian scored higher on 'socio-cultural liberalism'. This factor described a continuum that ranged from a resistance to change and a wish to maintain an established order, to an openness to change. Scores for 'pathology' were lower among younger gynaecologists. This meant that this age group tended to reject the view that a physical pathology is the most important aspect of treatment and the patients' lived experience would also be considered. Such different attitudes may impact the physician's response to patients as well as treatment outcomes.

Regarding specific CPP syndromes, a number of qualitative studies have explored women's experiences of living with endometriosis. Common themes found in the data included the experience of profound pain, dyspareunia, delays in diagnosis, the strain on relationships with partners, diminishing social relationships, negative impact on work, negative effects on emotional well-being, treatment, fertility and mixed thoughts about the future (Denny, 2004, 2009; Gilmour, Huntington, & Wilson, 2008; Huntington & Gilmour, 2005; Jones, Jenkinson, & Kennedy, 2004b). Thoughts about the future included a mixture of optimism and pessimism, with women more likely to feel optimistic if they had relief following surgery. Most of the women were worried that symptoms would return and were unsure of their ability to cope with the condition in the long-term (Denny, 2004). Other negative consequences of endometriosis included feelings of powerlessness and a fear that

the women's daughters would also develop the condition (Jones et al., 2004b). In another qualitative study that used an interpretive phenomenology (IPA) approach, Butt and Chesla (2007) recruited 13 women between the ages of 23 and 48 with endometriosis and their partners. The participants described how living with CPP due to endometriosis was an emotional and painful experience for couples, and how symptoms could disrupt everyday life as well as intimacy. Again, the women reported a delay in diagnosis, which had an adverse effect on their relationships with health providers. Reasons for the delayed diagnosis of endometriosis were investigated by (Ballard et al., 2006). Interviews with 32 women between the ages of 16-47 were conducted using thematic analysis. Possible reasons for delayed diagnoses included the normalisation of symptoms by women and doctors, the suppression of symptoms through hormonal medication, and the use of non-discriminatory investigations such as transvaginal ultrasounds, which result in a high number of false-negative results.

A limitation of the studies that have focused on women with endometriosis is that women with other CPP problems were not included, making the findings difficult to generalise to women with other CPP conditions. One study by (Schneider & Fletcher, 2008) explored the impact of IBS and inflammatory bowel disease (IBD) upon seven women between the ages of 18 and 22. Analyses followed a phenomenological method. Women commonly experienced an anxiety reaction followed by an attack of illness. The illness attack then had a negative impact on their emotional and physical well-being, which in turn affected their quality of life.

CPP treatment and interventions

Many women with CPP will be investigated by diagnostic laparoscopy. Moore, Ziebland, and Kennedy (2002) explored women's view of the risks and benefits of diagnostic laparoscopy. Participants were 20 women who were waiting to undergo a laparoscopy and a thematic approach was used to analyse the interviews. Although the women were aware of the risks involved with the procedure, it was found that they wanted to be given complete information about complication rates, what to expect during recovery, and the chances of finding a cause for their pain. Due to the multifaceted nature of CPP conditions, women with such conditions may benefit from a multidisciplinary approach to treatment. Using a content analysis approach, Sadownik, Seal, and Brotto (2012) explored the experiences of 19 women, aged between 20 and 54 with vestibulodynia, who participated in a Multidisciplinary Vulvodynia Program (MVP). The resultant themes that emerged included increased

knowledge, gained tools/skills, perceived improved mood or psychological well-being, a sense of validation and support, and an enhanced sense of empowerment. The authors concluded that the MVP was beneficial for women with vestibulodynia. However, the findings cannot be generalised to women with other CPP problems because the treatment was a vulvodynia-focused program and only women with vestibulodynia were recruited. Warwick, Joseph, Cordle, and Ashworth (2004) examined the subjective experiences of social support using interpretive phenomenological analysis. Eight women with CPP between the ages of 21 and 61 were recruited. The participants' views of helpful support included emotional and practical support. In addition, it was important for the support to be enduring, while at the same time maintaining the women's autonomy.

Souza et al. (2011) conducted a meta-synthesis of seven qualitative studies to analyse their contribution to improving treatment for patients with CPP. Four emergent themes were discussed. First, women reported secondary gains such as increased attention and affection from family members despite the global impairment the CPP had on the women's life. Consequently, the women may not be able to readapt to a life without pain and develop other complaints. Second, women in most of the studies had an overwhelming desire to know the cause of their pain. Third, the women in most of the studies had their own expectations regarding their doctor-patient relationship, which were in most cases dissatisfying. The final theme comprised gender issues which was highlighted in one study by Grace and MacBride-Stewart (2007). Interviews with 40 women between the ages of 22 and 51 (asked to reflect on 'how come' they have CPP) were analysed using a phenomenological approach. The narratives reflected an expectation that the pain should be 'visible' to reveal a physical pathology and to gain medical legitimacy. The pain was seen as 'normal' in the absence of a visible pathology, which led to the acceptance of the pain. The pain was also normalised by associating it with hormones, menstruation, and physical change after pregnancy, which are seen as things many women go through and are therefore unavoidable.

Female sexual pain

Sexual pain disorders are one type of female sexual difficulty that affects women's sexual and reproductive health and are poorly understood and often misdiagnosed (Harlow & Stewart, 2003). Vulvar pain occurring in the absence of an identified pathology is an increasingly common clinical problem and one that first appeared in the literature about 30

years ago (Moyal-Barracco & Lynch, 2003). Since then, there have been many different terms used to refer to this type of pain e.g., dysaesthetic vulvodynia, vulvar vestibulitis (VV), and idiopathic vulvar pain. Friedrich's (1987) original criteria for VV included pain on vestibular touch or attempted vaginal entry, tenderness to pressure within the vestibule, and physical findings confined to the vestibular erythema. In 2003, the International Society for the Study of Vulvovaginal Disease (ISSVD) recommended eliminating the use of the term vestibulitis and using vulvodynia as the preferred term for vulvar pain occurring in the absence of an underlying identified disease (Moyal-Barracco & Lynch, 2003).¹ Vulvodynia can be either generalized or localized and within each of these categories, classified as either provoked (PVD) (sexual, nonsexual, or both) or unprovoked vulvodynia.

Classification of sexual pain disorders

The Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV-TR defined vaginismus as "Recurrent or persistent involuntary spasm of the musculature of the outer third of the vagina that interferes with sexual intercourse" (American Psychiatric Association, 2000). Marked distress or interpersonal difficulty was required for a diagnosis and the symptoms could not be due to the direct physiological effects of a general medical condition (American Psychiatric Association, 2000). Prevalence data for vaginismus are scarce in comparison to dyspareunia, but range between approximately 1-6% (Schultz et al., 2005; Simon & Carey, 2001; van Lankveld et al., 2010). The DSM-IV-TR did not include genital pain as a primary feature of vaginismus, even though women diagnosed with vaginismus typically also experience pain (de Kruiff, Ter Kuile, Weijnenborg, & van Lankveld, 2000; Reissing, Binik, Khalife, Cohen, & Amsel, 2004). The key feature of vaginismus – vaginal spasms – has been confirmed in less than a third of women diagnosed with vaginismus and less than half of these women reported actually experiencing pelvic spasm during intercourse attempts (Reissing et al., 2004). Because the evidence did not support the DSM-IV distinction between dyspareunia and vaginismus, the fifth edition of the DSM (DSM-5) combined these into a single disorder called Genito-Pelvic Pain/Penetration disorder (GPPPD) (American Psychiatric Association, 2013; Binik, 2010; Ter Kuile, Both, & van Lankveld, 2010a). The diagnostic criteria for this disorder are "persistent or recurrent difficulties with one or more of the following: vaginal penetration during intercourse; marked vulvovaginal or pelvic pain

¹ The term vulvar vestibulitis will only be used when I discuss earlier studies where researchers employed this term to refer to participant inclusion criteria.

during vaginal intercourse or penetration attempts; marked fear or anxiety about vulvovaginal or pelvic pain in anticipation of, during, or as a result of vaginal penetration; marked tensing or tightening of the pelvic floor muscles during attempted vaginal penetration.” (p. 437). There is also the requirement that the symptoms have persisted for a minimum duration of approximately six months and cause “clinically significant distress” in the individual. It is estimated that approximately 15% of women in North America report recurrent pain during vaginal intercourse (American Psychiatric Association, 2013).

The DSM-5 does not specify diagnoses referring to pain outside of sexual activity such as CPP, generalised vulvodynia, and provoked vulvodynia. Intercourse may be one of many activities that provoke or aggravate pain. In the European Association of Urology (EAU) guidelines, distress or interference with intercourse is not necessary for a diagnosis of CPP, even though such factors are relevant to the patient in many cases (Engeler et al., 2016). Distress is also not a requirement for diagnosis with the International Classification of Diseases (ICD)-10 system (World Health Organization, 2008).

Etiology of female sexual pain

Psychosocial factors, including fear of sexual abuse and trait anxiety, are predictors of chronic painful intercourse (Harlow & Stewart, 2005; Khandker et al., 2011; Landry & Bergeron, 2011). Findings regarding past sexual and physical abuse as predictors of sexual pain have been mixed (Harlow & Stewart, 2005; Meana, Binik, Khalife, & Cohen, 1997).

Research on psychological and sexual functioning of women with sexual pain problems suggests that, compared with controls, they have higher levels of anxiety and psychological distress and lower levels of sexual satisfaction, sexual desire, and sexual self-esteem (Desrochers, Bergeron, Landry, & Jodoin, 2008; Gates & Galask, 2001; Masheb, Lozano-Blanco, Kohorn, Minkin, & Kerns, 2004). Hypervigilance for coital pain has been demonstrated in women with vulvodynia (Payne, Binik, Amsel, & Khalifé, 2005). In a qualitative study by Ayling and Ussher (2008) the majority of women with vulvodynia regarded themselves as “inadequate” and experienced feelings of shame, guilt, and a decreased desire for sexual contact. Nunns and Mandal (1997) found that, compared with controls, women with sexual pain had higher levels of state and trait anxiety as well as less sexual arousal and more negative feelings about sexual intercourse.

Women with vulvodynia also report poor quality of life (Xie et al., 2012). As well as an individual problem, sexual pain poses a huge economic burden, costing societies billions (Xie et al., 2012). Such costs relate to direct healthcare costs and indirect costs. Direct

healthcare costs include prescription medications, hospitalisations, diagnostic tests, and surgical procedures (Xie et al., 2012). Indirect costs include sick leave, job loss, unemployment, and housekeeping services (Xie et al., 2012). This large societal and economical impact of sexual pain highlights the need for effective assessment procedures and treatment options.

Many different treatments have been evaluated for the treatment of sexual pain. These include medical treatments [topical applications (Nyirjesy, Lev-Sagie, Mathew, & Culhane, 2009; Zolnoun, Hartmann, & Steege, 2003); injections (Pelletier et al., 2011; Rapkin, McDonald, & Morgan, 2008)], surgical treatments [e.g., vestibulectomies (Lambert, Bergeron, Desrosiers, & Lepage, 2012; Tommola, Unkila-Kallio, & Paavonen, 2011)], physical therapies [biofeedback, dilators, pelvic floor exercises, and electrical stimulation (Gentilcore-Saulnier, McLean, Goldfinger, Pukall, & Chamberlain, 2010; Goldfinger, Pukall, Gentilcore-Saulnier, McLean, & Chamberlain, 2009)], psychological therapies [cognitive behavioural therapy (CBT) (Engman, Wijma, & Wijma, 2010; van Lankveld et al., 2006), and hypnotherapy (Pukall, Kandyba, Amsel, Khalifé, & Binik, 2007)]. Based on the evidence, some attempts have been made to produce guidelines for the management of female sexual pain problems in clinical practice (Engeler et al., 2016; Mandal et al., 2010). These are discussed in more depth in the systematic review presented in Chapter 3.

Women with CPP and sexual pain problems

Women with CPP often experience pain with sexual intercourse (Denny, 2004; Denny & Mann, 2007; Zondervan et al., 2001) and report more sexual problems than patients with any other type of chronic pain (Collett, Cordle, Stewart, & Jagger, 1998). Some women experience CPP outside of sexual activity, whereas for others pain is exacerbated by sexual behaviour (Howard, 2012). This is because CPP affects structures involved in sexual activity including the vulva, vestibule, abdomen, and bladder (Howard, 2012). ter Kuile, Weijnenborg, and Spinhoven (2010b) found that women with CPP, compared with healthy controls, reported more vaginistic complaints, sexual avoidance, and sexual dissatisfaction.

Smith, Pukall, and Chamberlain (2013) investigated sexual and relationship functioning/satisfaction and vestibular pain sensitivity as well as the potential associations between these variables among women with provoked vestibulodynia (PVD). No difference in relationship satisfaction was found between women with PVD and controls, but women with PVD did report significantly less sexual satisfaction and higher vestibular pain ratings.

Lower heat pain thresholds were associated with less sexual satisfaction, and higher pain ratings were associated with lower sexual function and satisfaction among the women with PVD. Sexual problems have been associated with anxiety and depression, as well as a history of sexual abuse, which has been frequently documented among women with CPP (Collett et al., 1998; ter Kuile et al., 2010b; Walker et al., 1995). ter Kuile et al. (2010b) reported that anxiety and depression mediated the effect of CPP on sexual problems.

Research has shown that intimacy between romantic partners is associated with better sexual functioning. Bois, Bergeron, Rosen, McDuff, and Grégoire (2013) investigated sexual and relationship intimacy and their associations with sexual satisfaction, sexual function, pain self-efficacy, and pain intensity among women with PVD. Intimacy was defined as something that develops through a dynamic process involving the disclosure of thoughts, feelings, or personal information to a partner, who then responds in an understanding, validating, and caring way (Reis & Shaver, 1988). Sexual intimacy was therefore referred to as the disclosure between partners about sexuality and partner responsiveness and empathy during and following sexual interactions (Bois et al., 2013). In their study, Bois et al. (2013) found greater sexual intimacy was associated with higher sexual satisfaction, and higher pain self-efficacy during sexual intercourse (the belief one can control one's pain during sexual intercourse). Women's greater sexual and relationship intimacy were also associated with better sexual function.

Sexual intercourse may feel punishing for women with CPP because they may experience vaginal dryness, are more susceptible to irritation or infections, bladder or bowel irritation, or tightening of the pelvic muscles (Howard, 2012). In a qualitative study using empirical phenomenological analysis, Sutherland (2012) explored experiences of nine women, with an average age of 35 years, who experienced sexual discomfort and pain. The women described feelings of anxiety, vulnerability, loneliness, isolation, shame and inadequacy, and feelings of guilt and pressure to engage in sexual interaction. Themes of coping strategies included avoiding sexual encounters, engaging in self-care activities, releasing shame, guilt, and anger, and accepting the situation and keeping up hope. In another qualitative study using grounded theory, Donaldson and Meana (2011) explored the subjective experiences of early dyspareunia symptoms in 14 young women with an average age of 19. Themes included difficulties highlighting a problem, and that initial experiences of pain with intercourse were not particularly alarming. Personal attempts to control the pain were also reported, which led to negative personal and relationship consequences. Negative personal and relationship consequences included low self-confidence, embarrassment,

frustration, not being able to connect with their partners, resulting in emotional distance, and sexual tension that led to arguments. The difficulties highlighting a problem may reflect a lack of public health information, which can contribute to the delays in diagnosis and delays of treatment for potentially serious health problems.

The reasons women continue to have sexual intercourse despite pain experiences was explored using grounded theory by Elmerstig, Wijma, and Berterö (2008). Sixteen young women who had experienced coital pain in the last month took part. These authors found that participants were striving to fit their image of an ideal woman, which embodied a number of characteristics. These included the willingness to have sexual intercourse, being perceptive to their partner's needs, and being able to satisfy their partners. Having sexual intercourse, irrespective of pain or discomfort, was therefore considered as affirming them as "normal women." However, because the sample in this study was quite young (aged between 14 and 20, with an average age of 18), such ideologies of the ideal women may not be held by a mature sample. Other methodological problems included the fact that the studies conducted by Sutherland (2012), Donaldson and Meana (2011), and Elmerstig et al. (2008) only investigated women that experienced pain with intercourse, without specifying if the participants had underlying CPP conditions or any other relevant diagnoses. The inclusion/exclusion criteria in Sutherland (2012) were unclear and it is uncertain whether the women also experienced pain in situations other than sexual intercourse.

The impact of CPP on couples' relationships and sexual functioning was explored using thematic analysis in a study by Denny and Mann (2007). In a sample of 30 women with endometriosis between the ages of 19 and 44 years, the experience of dyspareunia impacted on quality of life and limited sexual activity, which was associated with lowered self-esteem. The women perceived tension and arguments with their partners as being due to the lack of sexual relations. Male partners tended to feel a sense of rejection and concern about their ability to please their female partners, despite knowing about their condition (Denny & Mann, 2007; Howard, 2012).

Measures used in CPP research

The problem with generic questionnaires

Patient reported outcome measures (PROMs) are questionnaires that patients complete in order to gauge their views on their own health (Devlin & Appleby, 2010). The main purpose of PROMs is to receive the patient's evaluation of their own health and/or health related quality of life rather than ask about treatment satisfaction (Devlin & Appleby, 2010). There are multiple uses of PROMs in clinical practice. For instance, they can be used as part of routine assessment and management for patients with long-term conditions such as CPP. They can be used to provide baseline information about patients' health, disease progression, disease regression, as well as treatment effects (Devlin & Appleby, 2010).

Despite there being a number of studies that have assessed the impact of CPP, the majority of studies have used either measures that were compiled only for the purpose of the study (Engel, Walker, Engel, Bullis, & Armstrong, 1998; Grace & Zondervan, 2006) or generic standardised measures, such as the Female Sexual Function Index (Masheb et al., 2004), Sexual Activity Questionnaire (Breton, Miller, & Fisher, 2008), the Hospital Anxiety and Depression Scale (Gurian et al., 2015; Romão et al., 2009), the World Health Organization Quality of Life-BREF scale (Romão et al., 2009; Tripoli et al., 2011), the Golombok-Rust Inventory of Sexual Satisfaction (ter Kuile et al., 2010b; Tripoli et al., 2011), the McGill Pain Questionnaire (Gurian et al., 2015), and the Short Form-12 Questionnaire (Chao, Abercrombie, Nakagawa, Learman, & Kuppermann, 2015). Despite the fact that these questionnaires have been evaluated and have demonstrated good validity, they have shown poorer face validity when used with women with CPP (Neelakantan, Omojole, Clarke, Gupta, & Khan, 2004). This is because these questionnaires do not cover all of the topics that women with CPP consider important or relevant to their condition. Therefore, when conducting research on participants with CPP, it is important to use a CPP-specific questionnaire to assess the impact of the condition on the well-being and functioning of the women.

Disease-specific questionnaires

There are a number of questionnaires that have been designed to focus on certain CPP conditions. For instance, questionnaires that assess endometriosis include a health-related quality of life (HRQOL) questionnaire (Colwell, Mathias, Pasta, & Henning, 1998) and the Endometriosis Health Profile (EHP)-30 (Jones, Kennedy, Barnard, Wong, & Jenkinson, 2001). Colwell et al. (1998) designed a HRQOL instrument intended to be used for women with endometriosis. The measure is a 95-item questionnaire that contains both generic and endometriosis-specific scales and items. In a validation study involving 137 women with

endometriosis, Colwell et al. (1998) found that the HRQOL measure had good internal consistency and construct validity. Most of the scales were also moderately to highly responsive to change for participants who had either improved or worsened pain/symptoms. Overall, the questionnaire is a reliable and valid measure that is responsive to changes in symptoms. Although the questionnaire was developed after reviewing relevant literature and conducting both clinician and patient panels, the finalised version consists mainly of items from the Medical Outcomes Study survey, a general HRQOL questionnaire (Stewart & Ware, 1992). Therefore, although the questionnaire can reliably assess the HRQOL of women with endometriosis, it likely does not cover the full spectrum of how the pain has impacted upon women's lives.

The EHP-30 (Jones et al., 2001) is one of the very few patient-generated questionnaires in this area. In-depth interviews were initially conducted to explore the impact of endometriosis on the participants' QoL, which informed the development of the questionnaire items. The questionnaire was then piloted on women with endometriosis to check the face validity of the items generated. The final questionnaire included a number of important domains such as the impact on work, perceptions of the medical profession, infertility, social support, and control and powerlessness. The EHP-30 has been found to have good internal consistency, construct validity, and test-retest reliability (Jones, Jenkinson, Taylor, Mills, & Kennedy, 2006; Jones et al., 2001). However, this questionnaire was designed specifically for women with endometriosis and therefore may not be suitable for women with CPP who do not have endometriosis.

There are also questionnaires that focus on interstitial cystitis (IC) which include the Interstitial Cystitis Symptom Index and Problem Index (ICSUPI) (O'Leary, Sant, Fowler, Whitmore, & Spolarich-Kroll, 1997) and the Pelvic Pain and Urgency/Frequency (PUF) Patient Symptom Scale (Parsons et al., 2002). O'Leary et al. (1997) initially developed a preliminary measure of the ICSUPI after extensive input from patient focus groups as well as clinicians with experience in diagnosing and treating women with IC. The final measure includes domains considered important to women with IC, including urinary symptoms, pain symptoms, sexual functioning, general health, symptom relationship with the menstrual cycle, and quality of life. O'Leary et al. (1997) were able to conclude that the ICSUPI has good psychometric properties and was able to discriminate well between characteristics of women with IC and those without.

Although the ICSUPI is useful for assessing a number of IC problems, it does not address pelvic pain other than bladder pain or symptoms associated with sexual intercourse.

Because of this, Parsons et al. (2002) developed the PUF Patient Symptom Scale. The PUF Symptom Scale was found to be a valid measure of IC symptoms and considered an accurate tool for detecting IC (Parsons et al., 2002). Like the endometriosis measures, the ICSIPI and PUF Patient Symptom Scale have both been designed to focus on symptoms that are related to IC. Furthermore, it is unclear how the authors generated the items for the PUF Patient Symptom Scale; if the items were not informed by women with IC, the measure's content validity may not be strong.

Measures that assess IBS include the Irritable Bowel Syndrome-Quality of Life Measure (IBS-QOL) and the IBS-36 (Groll et al., 2002; Patrick, Drossman, Frederick, Dicesare, & Puder, 1998). Patrick et al. (1998) generated the items of the IBS-QOL using qualitative interviews with individuals diagnosed with IBS. The psychometric properties of the IBS-QOL were evaluated in a cross-sectional survey and a repeat survey. The measure demonstrated high internal consistency, discriminant validity, and convergent validity. The IBS-36 was developed by Groll et al. (2002) with the use of focus groups, literature reviews, and IBS patients and specialists. The measure was initially pilot tested for content validity before being administered on a larger scale. It was reported that the IBS-36 has a very high internal consistency, test-retest reliability, and very good convergent validity. Although both the IBS-QOL and IBS-36 are useful in evaluating the health QOL in individuals with IBS, they may not be as useful in evaluating issues that are specific to women with CPP. This is because the items have been developed based on the input of both male and female individuals with IBS.

Finally, the Polycystic Ovary Syndrome Questionnaire (PCOSQ) was developed to assess the impact of polycystic ovary syndrome (PCOS) upon the QOL of women (Cronin et al., 1998). The PCOSQ was designed based on a number of principles, which included ensuring both physical and emotional health were measured, that the items reflected areas of functioning that were important to women with PCOS, and that the overall questionnaire should be short and easy to administer (Cronin et al., 1998). This was achieved through interviews with women with PCOS, reviewing the medical literature, and a survey of health professionals experienced in the management of PCOS. The PCOSQ has shown good content validity (Cronin et al., 1998), as well as good internal reliability, test-retest reliability, and construct validity (Jones et al., 2004a).

Most of the measures discussed above focus on health QOL, with little emphasis on sexual functioning. Sexual functioning is an important facet to consider when assessing the impact of CPP on women's lives. This is because women with CPP report significantly

decreased sexual function in comparison to pain-free women, as well as higher levels of pain with intercourse, sexual avoidance, and sexual dissatisfaction (Smith et al., 2013; ter Kuile et al., 2010b). One questionnaire that does assess sexual functioning is the revised Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire (PISQ-IR), which was developed to assess sexual functioning in women with pelvic floor disorders (PFD) (Rogers et al., 2013). The PISQ-IR was designed to be suitable for women with and without a sexual partner because some women may be sexually inactive as a consequence of their symptoms. The PISQ-IR has been shown to be a reliable, valid, and responsive measure of sexual function in women with PFD.

The disease-specific questionnaires that have been discussed are important for evaluating the impact of disease-specific symptoms on QOL. However, limitations of some of the questionnaires include not taking a patient-led approach when generating the items (Colwell et al., 1998; Parsons et al., 2002) and not considering important areas of life affected by the pain, such as work, relationships, and social life (Parsons et al., 2002). Moreover, these questionnaires do not adequately evaluate the impact of CPP on personal relationships, which is very important based on the findings from previous qualitative studies (Butt & Chesla, 2007; Smith et al., 2013; Sutherland, 2012). Finally, some questionnaires focus on the characteristics of pain symptoms (e.g., intensity, duration, pain during sex) with little focus on the impact of the pain (O'Leary et al., 1997; Parsons et al., 2002).

Why develop a new CPP questionnaire?

Although questionnaires that focus on specific CPP conditions are important, a questionnaire that can be used to assess the impact of various CPP conditions on women's lives would have versatile uses. For example, such a questionnaire would be able to be used by women who have not received a diagnosis for their pain. Because CPP is associated with a number of different conditions, including endometriosis, chronic urinary tract infection, and IBS, treatment usually requires treating the pain itself or the possible treatment of specific conditions (Green, Cohen, Finkenzeller, & Christo, 2010; Howard, 2003). A CPP questionnaire that is not specific to a CPP condition would be useful in evaluating treatments that are not specific to a CPP condition. Such treatments can include pharmaceutical treatment, psychotherapeutic, and multidisciplinary interventions.

Current CPP questionnaires

Current CPP questionnaires include the CPP questionnaire (van Os-Bossagh et al., 2002) and CPP Questionnaire (CPPQ)-Mohedo test (Mohedo et al., 2013). van Os-Bossagh et al. (2002) developed the CPP questionnaire to be used as a screening test for diagnosing CPP. The CPP questionnaire assesses a number of chronic symptoms in the pelvic region, including lower abdominal pain, low back pain, voiding problems, and pain with intercourse. Women completing the questionnaire indicate the occurrence of the symptoms on a five-point scale ranging from “never” to “always”. Apart from the items that concerned voiding symptoms and dyspareunia, the questionnaire overall demonstrated good construct validity and internal consistency (van Os-Bossagh et al., 2002). The purpose of the CPP questionnaire is to offer an inexpensive, easy to use tool in CPP diagnosis and screening. Because of this, the CPP questionnaire items are more symptom-focussed and the measure was reviewed and informed by pelvic pain experts, including gynaecologists, psychologists, general practitioners, and general surgeons. The items on the CPP questionnaire, however, do not assess the psychological impact of CPP nor how the pain has impacted the women’s QOL.

The CPPQ-Mohedo was developed to measure CPP in both male and female individuals (Mohedo et al., 2013). It is based on the National Institutes of Health-Chronic Prostatitis Symptom Index (NIH-CPSI), which was designed to measure symptoms and the impact of prostatitis on daily life in men (Collins et al., 2001). Items in the CPPQ-Mohedo were adapted to include questions that are relevant to female anatomical sites. Experts from urogynaecology, obstetrics, and coloproctology assessed the questionnaire as a research tool. After the second evaluation, the CPPQ-Mohedo was pilot tested to check the comprehension of the questions and the measure had good discriminant validity for both sexes and good internal consistency (Mohedo et al., 2013). Like the CPP Questionnaire, the CPPQ-Mohedo was designed to be used as a tool to detect CPP but in both male and female individuals. A patient-led approach was not used in the development of the CPPQ-Mohedo and the questionnaire focuses strongly on symptoms rather than the impact of CPP on everyday life.

There currently is no existing measure that assesses the impact of CPP on women’s lives that is suitable for women with different diagnoses. As previously discussed, the use of generic questionnaires has poorer face validity when used with women with CPP and also has the limitation of not being sensitive enough to assess changes in health-related QOL (HRQOL) across a variety of diseases (Jones, Kennedy, & Jenkinson, 2002; Neelakantan et al., 2004). The disease-specific questionnaires can only be used by women with a clear

diagnosis. Many women with CPP are not diagnosed with an underlying condition and CPP has been considered to be a syndrome in its own right (Chao et al., 2015; Grace & Zondervan, 2006; van Os-Bossagh et al., 2002). A generally accepted questionnaire assessing pain, symptoms, and QoL in patients with CPP is needed to facilitate the interpretation and comparison of studies and compare data reliably (Quaghebeur & Wyndaele, 2013).

Aims and research questions

This thesis aimed to explore the experiences of women with CPP and provide a thorough review of research examining different treatments and interventions for women experiencing sexual pain. In addition, a specific objective was to develop a new PROM that assesses the impact of CPP on women's lives, including how the pain impacts everyday tasks, work, social functioning, relationship satisfaction, sexual functioning, and emotional wellbeing. To address these aims, the following research questions were examined: (1) Which treatments for female sexual pain have been evaluated in clinical studies? (2) What is the effectiveness of these treatments? (3) When follow-ups are carried out, are improvements in sexual functioning, satisfaction, or pain maintained? These questions were addressed in a systematic review. (4) How do women with CPP cope with their pain and how do they perceive the impact of their pain on their life in terms of work, socialising, hobbies, exercise, and personal relationships? (5) Which areas in life that have been affected by the pain do women consider important? These were addressed using qualitative methods. (6) Does the new CPP questionnaire have good face validity, convergent validity, and reliability? This question was addressed using both qualitative and quantitative methods.

Thesis outline

The remainder of the thesis is comprised of six chapters. Chapter 2 outlines the methodological approach used in this thesis and discusses methodological issues. Chapter 3 presents a systematic review of treatments for female sexual pain problems. Chapter 4 reports the findings of a qualitative study that explored the experiences of women with CPP conditions. Chapter 5 reports the findings of the first stage of the development of a questionnaire that assesses the impact of CPP on women's lives. This was a pilot study that used qualitative methods to assess the face validity of the questionnaire items. Chapter 6

presents the findings of the second stage of the questionnaire development and assesses the reliability, validity, and psychometric properties of the new CPP questionnaire. Chapter 7 consists of a general discussion of the overall thesis.

Chapter 2: Methodology

This chapter includes a review of the research methods, study designs, and a discussion of the populations and samples used. As stated in Chapter 1, the aim of this research was to explore the experiences of women with CPP and to develop a measure of CPP that is reflective of such experiences. Initially, a thorough review of research examining different treatments and interventions for women experiencing sexual pain was conducted. Following this, a mixed methods design was used, comprising qualitative and quantitative studies.

Quantitative vs qualitative research methods

Quantitative approaches have had a dominant role in psychology with qualitative methods being accepted relatively recently (Howitt, 2010). These approaches are based on quite different philosophical foundations. Quantitative methods stem from a positivist epistemology, which stresses the importance of observation in obtaining knowledge (Howitt & Cramer, 2011). For instance, positivism is characterised by universal laws, quantification, and the rejection of metaphysics (Howitt, 2010; Howitt & Cramer, 2011). On the basis of this premise, it is assumed that there is a reality that research aims to tap into. In contrast, qualitative approaches reject the idea of an observable, independent, and universal reality (Braun & Clarke, 2013; Howitt & Cramer, 2011). Instead, individuals operate through a subjective window that is influenced by culture, expectations, and general view on life. On this premise, it is viewed that there is a reciprocal relationship between the individual and context under study (Braun & Clarke, 2013).

Both quantitative and qualitative approaches have their advantages and disadvantages. Quantitative research methods are useful when addressing clearly specified research questions (Howitt & Cramer, 2011). This is because quantitative research methods can be used to control data collection and make causal inferences by isolating the effects of particular variables; however, this is not the case with cross-sectional or correlational designs. Though quantitative research designs tend to be used to address specific hypotheses, it has been argued that they have also been used to develop research questions (Pelto, 2015). Pelto (2015) argued that large numbers of research projects have used structured surveys to determine frequencies of particular events (e.g. illnesses, physical activity, or drug use) without the intention of testing specific hypotheses. Such surveys are said to be used as

“situation assessments” before the development of interventions, which can be considered as a more inductive process (Pelto, 2015). A limitation of quantitative methods is that complex phenomena is reduced into measureable categories that are intended to be generalised to wider or similar contexts. Findings may be generalised at the expense of accuracy because such generalised findings may not be accurate representations of single cases (Winter, 2000). In addition, there is always the risk that the characteristics of the sample are not true reflections of reality (Howitt & Cramer, 2011). Finally, the information gained from participants is much more restricted, which can lead quantitative researchers to miss out on new information or data.

Qualitative research methods have the advantage of allowing the researcher to gain a deeper understanding of the individual’s perspective in a more natural setting (Howitt & Cramer, 2011). Because qualitative research methods aim to gain rich, detailed data, such methods are useful when there is generally little or limited research on a topic. Qualitative researchers tend to accept a post-positivist view, in which regardless of what true reality there is, knowledge of reality can only be approximate and there are multiple versions of “reality” (Howitt, 2010; Howitt & Cramer, 2011). Unlike in quantitative methods, data collection using qualitative methods are not as controlled and the data cannot be used to predict or explain the relationship between variables. Thus, qualitative methods tend to be more inductive, rather than deductive (Braun & Clarke, 2013).

Given the strengths and weaknesses of both quantitative and qualitative approaches, a specific approach is chosen depending on the research goals. Rather than be treated as competing paradigms, mixing both quantitative and qualitative methods can be very useful (Jick, 2006 ; Todd, Nerlich, McKeown, & Clarke, 2004). The term “triangulation” has been used to describe mixing methods and has been defined by Denzin (1989) as “the combination of methodologies in the study of the same phenomenon” (p. 291). The intention is to take advantage of both methods for a more accurate representation of the research topic. This also means the different levels of a particular phenomenon can be studied by mixing methods. Another advantage of the use of a mixed methods approach is that it can lead to improvements in the development of theories (Todd et al., 2004). This is because these approaches force researchers to consider the depth and breadth of their research. Researchers would need to reflect on the differing theoretical perspectives and the relationships between data sets from different methods (Todd et al., 2004).

An example of mixed methods research was a study conducted by Doorenbos (2014). The aim of the research was to understand the pain management experience among American

Indians. A number of barriers to researching chronic pain management among American Indians were highlighted, which included the relatively small number of this population group and the widespread racial misclassification. A mixed methods approach was used to understand the complex experiences among American Indians using the strengths of quantitative and qualitative research designs. Quantitative data included the examination of national databases to assess trends, as well as more detailed clinical data that was used to identify American Indian populations, evaluate breakdowns in the delivery of care, and processes that led to unsuccessful outcomes. Qualitative data was obtained through focus groups to provide more refined information about perceptions of care that was received or recommended. The qualitative data gave further insight into the potential barriers to care and views of chronic pain care that are not easily recognised in clinical records.

Although mixed methods can be beneficial in gaining a greater understanding in findings, there are methodological issues that need to be considered. First, it is important for researchers to define exactly what mixed approaches have been used (Bazeley, 2004). This is especially true when considering the availability of a wide range of qualitative and quantitative research approaches. Second, reasons for choosing a mixed methods approach need to be made clear as this can lead to confusion during the research design phase (Bazeley, 2004). A study is likely to be more thorough and focused in the presence of a clear rationale because data would be included in relation to the study aim rather than just because of its availability (Creswell, Fetters, & Ivankova, 2004). Thirdly, there are concerns surrounding whether the quantitative and qualitative components are in fact integrated or whether they stand alone (Bryman, 2006). In cases where the different components are kept separate, it can be questioned whether they can be considered mixed methods studies rather than two studies (Bazeley, 2004). Finally, differences in the nature of the term ‘validity’ between qualitative and quantitative research need consideration. For example, external validity is of greater importance for quantitative research while being of little importance for most qualitative research (Winter, 2000). According to Maxwell (1992): “A method by itself is neither valid nor invalid; methods can produce valid data or accounts in some circumstances and invalid ones in others. Validity is not an inherent property of a particular method, but pertains to the data, accounts, or conclusions reached by using that method in a particular context for a particular purpose” (p. 284). Therefore, in mixed research designs, it is important to examine the research process as a whole, rather than focus on specific measurement, scores, and instruments in relation to validity.

For the current thesis, it was useful to adopt both qualitative and quantitative research methods. This is because the aims were to develop a new measure that is grounded in the views of women with CPP and to assess its psychometric properties. Qualitative methods were useful for exploring the impact of CPP on women's lives and the data were used to inform questionnaire development. Qualitative methods were also deemed most appropriate for the pilot study that aimed to investigate participants' perceptions of the original version of the questionnaire. The questionnaire was then revised based on participants' feedback during the pilot study. Quantitative methods were used to test the reliability and validity of the revised version of the questionnaire.

The construction of psychological measures/scales

Standardised scales or measures are very important tools in psychological research. A scale can be considered to be standardised if it is able to produce consistent results by ensuring it can only be administered in a certain way (i.e., the same instructions, scoring procedures, and materials are used) (Howitt & Cramer, 2011). A scale can also be considered to be standardised if interpretation of its scores is consistent through the use of normative data (Howitt & Cramer, 2011). There are a number of validated, standardised measures that have been used in psychological research, including to assess variables such as pain, mood, attitudes, and intelligence tests. However, in some instances there may not be valid or reliable measures available to assess a construct of interest. It is in such instances where the development of a new measure is warranted.

Measures can be either unidimensional or multidimensional. Unidimensional scales measure a single underlying dimension, whereas multidimensional scales measure a number of underlying dimensions which are correlated with one another (Howitt & Cramer, 2011; Kothari, 2004). Both types of scales are useful depending on what is being measured. For instance, a unidimensional scale would be useful when assessing maths ability, time, or verbal ability. Multidimensional scales would be more appropriate when assessing abstract concepts such as intelligence, self-esteem, or happiness. This is because such concepts are likely determined by a number of different factors e.g., a number of factors would need to be considered when measuring academic achievement, including maths, verbal, and reading ability. Therefore, when constructing a new scale, it is important to be able to specify the nature of the concept as this can help identify any relevant factors that need consideration

(Howitt & Cramer, 2011). It may be appropriate to measure a number of factors that are closely related and are part of the concept in question.

After defining the concept of interest and reflecting on all of its features, an initial pool of items is generated. It is important to appreciate how the wording of questions greatly impact the way respondents answer (Bradburn, Sudman, & Wansink, 2004). It is important that the items are as unambiguous and as clear as possible. To ensure clarity, items should: consist of short, simple sentence structures; use simple language that is appropriate for the target group and avoid complex grammar; and avoid leading questions, which may lead participants to answer items in a certain way (Bradburn et al., 2004; Howitt & Cramer, 2011; Pett, Lackey, & Sullivan, 2003). It is also important to research the topic of interest to check that the items tap into all of its dimensions to ensure the measure has satisfactory construct validity. Ways in which this can be achieved is by investigating what previous researchers regarded as important, what focus groups or interviews with the target population perceive as important when asked about the topic, as well as what empirical evidence has considered to be important dimensions of the topic of interest (Howitt & Cramer, 2011). It is expected that the initial pool of items will be revised several times to ensure the area of interest is fully covered, and that confusing and redundant items will be removed (Pett et al., 2003).

An important aspect of the development of a measure is determining the type of scaling to be used and the number of response categories. Common scaling approaches include Thurstone scaling, Guttman scaling, graphic rating scales, visual analogue scales, and Likert-type scales (Pett et al., 2003). The choice of scaling depends on the aim of the measure (Kothari, 2004).

Thurstone scales are constructed using a consensus approach whereby items are selected by a panel of judges who evaluate the relevance of the items and their level of ambiguity. After the scale has been developed, respondents are asked to check only the statements they agree with. An average score of the statements is then calculated, which quantifies their opinion on the topic. Although the Thurstone method has been used for the development of various attitude scales, there are limitations. The development of Thurstone scales can be time consuming and costly. In addition the process of selecting the items involves a subjective decision making process on the part of the judges and may reflect their own attitudes.

Guttman scales consist of a series of statements to which respondents indicate their level of agreements or disagreement. A key feature of Guttman scales is that the items are cumulative. Therefore, if a respondent replies favourably to item 5 on a 10 item scale, then it

is expected that they would have also replied favourably to items 1 to 4. An individual's score is calculated by adding the points of the items that were answered favourably. The total score will reflect an individual's attitude or latent trait along a continuum. A limitation of the Guttman model is that in practice it is very difficult to develop a perfect cumulative scale. In addition, Guttman scales can only be used to assess unidimensional traits.

Graphic rating scales (GRS) consist of items that are rated along a continuum with various points that run from one extreme to another. The respondent is able to mark their rating anywhere along the line. Though GRS are simple to construct and are commonly used, the answers can be difficult to analyse since the respondent is able to mark almost anywhere along the line. Visual analogue scales (VAS) typically consist of a 10-centimetre line with opposing statements anchored at each end. Like with the GRS, respondents can place a mark anywhere along the line.

Likert-type scales consist of statements that reflect either a favourable or unfavourable attitude. Participants are asked to rate their level of agreement with the various statements. Typical Likert scales consist of five response categories that range from "strongly disagree" to "strongly agree" with "neither agree nor disagree" in the middle. Some use a 7-point, 9-point scale, or 4-point scale to produce a forced choice. Likert scales are commonly used, easy to construct, simple to use, and tend to produce highly reliable scales (Bertram, 2006). However, there are also a number of limitations. First, equal distances between the response categories used in Likert scales cannot be assumed. Therefore, it is unclear how much an individual is in agreement or disagreement with the different statements. Second, a total score can be achieved by a variety of response patterns, which makes it difficult to interpret. Third, respondents may answer in socially desirable ways rather than indicate their true attitudes (especially if the scale is asking about a controversial topic).

There are a number of response scales to choose from, which can make it difficult to decide on which type to use. Hasson and Arnetz (2005) evaluated and compared the validity and reliability of self-rating scales that used VAS and Likert-type response options based on single-items and multiple-item indices that measured the same construct. The researchers found that the VAS and Likert items measuring the same construct were highly correlated and were both comparable in terms of reliability. Overall, it was concluded that there was no clear evidence that either VAS or the Likert scales were superior to one another from a statistical point of view and the context of application and circumstances of use is of greater importance. In a different study, Lund et al. (2005) evaluated the quality of the intra-individual assessments of self-reported pain intensity on a VAS and a discrete five category

verbal rating scale (VRS), in patients with pain. The VAS contained the anchor statements “no pain” and “worst possible pain”. The VRS consisted of a 5-point scale with the following response categories: “no pain (0),” “mild (1),” “moderate (2),” “severe (3),” “worst possible pain (4).” Greater agreement within repeated individual records was found with the VRS compared with the VAS for the assessment of pain (a subjective phenomena). The authors suggested that this could have been due to the use of verbal descriptors or the use of only five categories. It was also suggested that subjective perceptions, such as pain, could be more easily expressed in words than by a mark on a continuous line without operational definition or by numbers.

It is very important to pre-test or pilot a newly developed measure with a sample that is representative of the population of interest. It may be that key questions are not understood by participants, that the questions are not as clear as was expected, or that there are other problems that the researchers were not aware of (Bradburn et al., 2004; Burgess, 2001). During the pilot phase, respondents should be encouraged to be open and to feel free to criticise the preliminary version of the measure (Bradburn et al., 2004; Pett et al., 2003). Feedback during the pilot phase may suggest that some items are unclear and need to be revised or removed. It would also be useful at this stage to ensure the items are ordered appropriately and to highlight whether any dimensions of the topic have been missed.

Once the newly developed measure has been piloted, the next stage is to refine it through either item-whole analysis or factor analysis (Howitt & Cramer, 2011; Pett et al., 2003). Item-whole analysis reduces the number of scale items by correlating individual item scores with the total scale score (Howitt & Cramer, 2011). It is theorised that the total scale score should measure the same construct as each individual item. Therefore, if an item does not correlate with the total scale score, it is assumed to be measuring a different construct and is consequently removed (Howitt & Cramer, 2011). By removing items in this way, it is anticipated that a more concise and consistent measure is produced. An advantage of this approach is that it is relatively simple to achieve and is useful in obtaining a unidimensional scale (Howitt & Cramer, 2011). However, item-whole analysis does not provide information about the structure of the measure and may not always be successful at achieving a unidimensional measure (Howitt & Cramer, 2011).

The alternative approach is to conduct a factor analysis. In a factor analysis, a matrix of correlations between all the items is calculated. Items that are highly correlated with one another but are relatively independent of other subsets of highly correlated items are grouped into factors (Tabachnick & Fidell, 2014). Factors are empirically based hypothetical variables

that consist of items that are highly correlated and represent a specific underlying dimension of the construct of interest (Howitt & Cramer, 2011; Tabachnick & Fidell, 2014). Factor analysis aims to reduce the number of items, to summarise the patterns of correlations between items, and/or to test a theory about the nature of the underlying dimensions (Tabachnick & Fidell, 2014). Unlike with item-whole analysis, factor analysis is able to provide a comprehensive representation of the structure of the measure.

There are two broad types of factor analyses, namely exploratory and confirmatory factor analysis. Exploratory factor analysis (EFA) is used when the interrelationships and number of factors among a group of items, indicators, or characteristics is unknown (Pett et al., 2003; Tabachnick & Fidell, 2014). In such instances, EFA is used to explore the underlying dimensions of a construct of interest (Pett et al., 2003). Confirmatory factor analysis (CFA) is used to assess the extent to which factors identified within the data fit a hypothesised structure (Pett et al., 2003). Therefore, CFA is used when there is some knowledge about the underlying dimensions of the construct of interest (Pett et al., 2003; Tabachnick & Fidell, 2014). CFA can be used to assess theories or models that predict the relationships among a set of factors, to investigate the utility of underlying dimensions of a construct that have been identified through EFA, as well as compare factor structures across different studies (Pett et al., 2003).

Quality criteria for measurement properties

Quality criteria for the properties of measures are important. Such criteria can help determine the methodological quality of studies and serve as useful tools for the evaluation of different measures. Terwee et al. (2007) defined a set of quality criteria for measurement properties, including the design, methods, and outcomes of studies on the development of health status questionnaires. The quality criteria outlined by Terwee et al. (2007) was used as a useful tool in the current research to help ensure quality in the development of the new CPP measure. Terwee et al. (2007)'s criteria includes all of the following measurement properties, which will be discussed in turn: content validity; internal consistency; criterion validity; construct validity; reproducibility; responsiveness; floor and ceiling effects; and interpretability.

Content validity

Content validity refers to the extent to which the measure is representative of the different elements of the construct of interest (Shuttleworth, 2009). Terwee et al. (2007) suggested providing a positive rating for content validity if a clear description of the questionnaire aim, the target population, the concepts intended to be measured, and item selection is provided. The authors argued that the questionnaire aim is important because different items may be valid for different aims. For example, if the questionnaire aims to evaluate the outcome of an intervention, the items need to be reflective of this. The target population is important to highlight because this will allow demonstration of the relevance of the questionnaire and whether the items are comprehensive enough. Terwee et al. (2007) also highlighted the importance of reporting the methods of item selection, item reduction, and the implementation of a pilot study to assess the readability and suitability of the questionnaire. Because items should be reflective of the target population, item selection should involve those from the same population group.

Internal consistency

Internal consistency refers to the extent to which the items in a questionnaire correlate with one another, which will theoretically indicate that the items are measuring the same construct (Terwee et al., 2007). To assess internal consistency of a new measure, it is useful to initially conduct a factor analysis to determine the number of dimensions within the scale. As previously discussed, EFA should be applied where there is no prior knowledge of the factor structure of the questionnaire (Tabachnick & Fidell, 2014) and a CFA should be used if there is a clear hypothesis regarding the dimensionality of the questionnaire (Tabachnick & Fidell, 2014). Terwee et al. (2007) also recommended that a Cronbach's alpha should be calculated for each dimension separately. Cronbach's alpha is the most widely used objective measure of internal consistency (Tavakol & Dennick, 2011). The value of alpha is increased if items are correlated with each other (Tavakol & Dennick, 2011). However, an alpha that is too high may suggest redundancy of some items as they are likely to be asking the same question (Tavakol & Dennick, 2011). It is generally recognised that an acceptable value of alpha should range between 0.7 to 0.9 (Tavakol & Dennick, 2011; Terwee et al., 2007). A low alpha could suggest low correlations between items, a low number of questions, or heterogeneous constructs (Tavakol & Dennick, 2011; Terwee et al., 2007). If the alpha is low due to low correlations between items, then they should be either removed or revised (Tavakol & Dennick, 2011; Terwee et al., 2007).

Criterion validity

Criterion validity is considered to comprise predictive validity and concurrent validity (Cronbach & Meehl, 1955). Essentially, criterion validity refers to how well the questionnaire is able to predict the criterion of interest (Cronbach & Meehl, 1955). To assess criterion validity, the criterion of interest is measured using the newly developed questionnaire as well as an independent measure of the same criterion (Cronbach & Meehl, 1955). Predictive validity is being assessed if the criterion is obtained some time after the questionnaire was administered (Cronbach & Meehl, 1955). Concurrent validity is assessed if the questionnaire and criterion is determined at the same time (Cronbach & Meehl, 1955). According to Terwee et al. (2007), a positive rating for criterion validity is warranted if scores on the questionnaire correlate with a “gold standard” measure of the criterion of interest.

Construct validity

According to Terwee et al. (2007), construct validity refers to whether scores on a particular instrument relate to other measures in a way that is consistent with theoretically derived hypotheses and theories. For example, to support whether a test measures a particular construct, the pattern of correlations between the measure and measures of other constructs should be in line with how they are theoretically predicted to correlate (DeVellis, 2003). This may sound similar to criterion validity. However, construct validity is about specifying the nature of the psychological construct and therefore relates more to theory development rather than simply addressing whether a test measures what it is supposed to measure (Cronbach & Meehl, 1955; Howitt & Cramer, 2011). For instance, the predictive and concurrent validity of a new measure of self-esteem may be assessed against certain criteria, such as existing measures of self-esteem. However, if the new measure of self-esteem was based on a new theoretical conceptualisation, then correlating it with existing measures that differ in their theoretical assumptions of self-esteem would result in findings that indicate poor criterion validity. In such instance, the construct validity of the new self-esteem measure can be investigated by comparing it to measures of theoretically related constructs (e.g. self-confidence).

Other types of validity, namely convergent and discriminant validity, can be considered to fall under construct validity (Howitt & Cramer, 2011). Convergent validity

refers to the extent to which a measure of a particular construct relates to other measures of the same construct irrespective of the nature or mode of the measures (Howitt & Cramer, 2011). For example, a new self-report intelligence scale should correlate with exam performance. Discriminant validity is the opposite of convergent validity and reflects the need for measures that assess different constructs to show low or moderate correlations with each other (Howitt & Cramer, 2011).

Reproducibility

Reproducibility or test-retest reliability refers to how consistent the measurement scores are with repeated administration of the measure. To assess this, questionnaires are given to a group of participants on two or more separate occasions. The scores from the first and subsequent occasions are then correlated with each other (DeVellis, 2003a). If the measure is a true reflection of the construct of interest, then it is predicted to assess the construct comparably on both occasions (DeVellis, 2003a). It should be noted that reproducibility is only relevant for constructs that are relatively stable over time (e.g., traits) rather than situational constructs (e.g., states).

The issue with reproducibility or test-retest reliability is that it is possible that the correlation of the scores from separate occasions may not be a reflection of measurement properties. For instance, if items were influenced by social desirability as well as the construct of interest, stable responses may be elicited even if the construct of interest has changed (Nunnally, 1978). In addition, it may be that the construct of interest has changed, leading to changes in scores, which in turn may be attributed to unreliability. Kelly and McGrath (1988) highlighted four confounding factors when examining test-retest scores. First, changes in scores may be due to real changes in the construct of interest. Second, changes in scores may reflect natural oscillations of the construct of interest (e.g., time of day or month). Third, different scores may reflect errors made by participants or measurement methods (such as fatigue, or misreading the items). Finally, differences in scores may reflect an unreliable measure. Note that reliability is only one out of the number of factors listed. Terwee et al. (2007) suggested that the time period between administrations should be long enough to prevent recall, but short enough so that clinical changes have not occurred. These authors also indicated the importance of describing and justifying the selected time period.

Responsiveness

Responsiveness refers to the ability of the measure to be able to detect clinically important changes over time (Terwee et al., 2007; Terwee, Dekker, Wiersinga, Prummel, & Bossuyt, 2003). There have been a great number of inconsistencies in the definitions used to describe responsiveness (Terwee et al., 2003). These include whether the measure is able to detect clinically important changes, changes due to treatment effects, or changes in the true value of the underlying construct (Terwee et al., 2003). Some also regard responsiveness as an element of construct validity (Lohr et al., 1996). Terwee et al. (2007) considered responsiveness to be a measure of longitudinal validity and recommended that it be assessed by examining predefined hypotheses. For example, there may be expected differences in changes between known groups. Responsiveness can also be measured by assessing whether the questionnaire is able to distinguish between those who have and have not changed according to an external criterion e.g., functional status (Terwee et al., 2007; Terwee et al., 2003).

Floor or ceiling effects

A floor effect occurs when more than 15% of participants score within the lower limit for potential responses (McHorney & Tarlov, 1995). A ceiling effect is the opposite and occurs when more than 15% of participants score within the upper limit for potential responses (McHorney & Tarlov, 1995). When either floor or ceiling effects occur, participants with the lowest and highest scores cannot be distinguished easily (Fries, Rose, & Krishnan, 2011; Terwee et al., 2007). This negatively impacts reliability and the measure's responsiveness because changes cannot be measured (Fries, Rose, & Krishnan, 2011; Terwee et al., 2007). The presence of floor and ceiling effects may indicate a lack of content validity and may be a consequence of the absence of extreme items in the lower or upper limit of the measure (Terwee et al., 2007).

Interpretability

Interpretability refers to the meaningfulness of scores that are obtained from the measure or how well qualitative meaning can be assigned to quantitative scores (Lohr et al., 1996; Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006). Understanding the meaning of scores will help determine whether a clinically meaningful change has occurred. However, within healthcare or clinical research, perceptions of what is considered to be a meaningful change in score likely differ between the respondent and whoever is administering the measure. From the perspective of the patient, a change in score may only be seen as meaningful if it reflects a change in symptoms and/or functioning (Crosby, Kolotkin, & Williams, 2003). For a clinician, a meaningful change may be related to the prognosis of the disease or a change in treatment (Crosby et al., 2003). Terwee et al. (2007) suggested that investigators should provide information about what change in score would be clinically meaningful and recommended “anchor-based” approaches to determine the minimal important change in scores rather than distribution-based approaches that rely on sample characteristics. Anchor-based approaches use an external criterion to operationalise change in scores (Crosby et al., 2003; Terwee et al., 2007). Terwee et al. (2007) suggested a number of types of information that can be used to interpret questionnaire scores, including means and standard deviations of reference populations or norm scores; relevant subgroups that are expected to differ in scores (e.g. gender, age, diagnoses, etc.); and patient groups before and after treatment.

Likert response formats and the use of parametric statistics

A controversial issue within psychometric research in health science is the treatment of data from Likert-type response formats (which are traditionally ordinal) as interval data. Ordinal scales are scales that include item responses which reflect an ordered structure (Svensson, 2001). For example, an item on a scale may consist of the following response options: Never, Occasionally, Frequently, Always. Researchers may decide to assign the numerals 1, 2, 3, and 4 to these categories. The assigned numerals are a reflection of the rank order of the response categories with no absolute value (Kothari, 2004); differences between the values cannot be assumed to be equal (Jamieson, 2004). Because ordinal scales only reflect rank order, the most appropriate measure of central tendency is the median (Kothari, 2004). Percentile or quartile measures are most appropriate for measuring dispersion (Kothari, 2004). In addition, statistical significance testing is limited to non-parametric tests.

In contrast, interval scales consist of an arbitrary zero point and a unit or measurement that is consistent throughout (Knapp, 1990). Interval scales can be considered statistically more powerful than ordinal scales, with the use of the mean and standard deviation as the most appropriate measures of central tendency and dispersion, respectively. A limitation of interval scales is the lack of a “true” zero point and the inability to measure the absence of a characteristic (Kothari, 2004). For instance, the zero point on the Celsius scale measuring temperature is arbitrarily set and does not reflect the absence of temperature (Kothari, 2004).

As discussed, Likert-scales are categorised as ordinal scales because the response categories have a rank order and the distance between them cannot be assumed to be equal. However, many researchers assume that they are and many papers have been published that have described and analysed data from Likert scales with the use of means, standard deviations, and parametric tests (Jamieson, 2004). As pointed out by Jamieson (2004), it is important to address the legitimacy of assuming an interval scale for Likert categories because the appropriate statistics differ for ordinal and interval variables. Therefore, using the wrong statistics may lead to incorrect conclusions about the significance of the findings. Jamieson (2004) noted that it is not clear whether authors are aware of this issue as they seldom discuss their assumption of interval status for Likert data with any supporting statements or arguments.

The ordinal/interval debate has been a longstanding one and there appears to be as many for, as well as against, the treatment of ordinal scales as interval data (Knapp, 1990). Those that adopt a more ‘conservative’ or ‘purist’ view believe that once data has been assigned to an ordinal level, analysis will inevitably have low power and is limited to medians, modes, rank correlations, and non-parametric procedures (Knapp, 1990). Authors that hold such views include Kuzon, Urbanchek, and McCabe (1996) who discussed the use of parametric analysis for ordinal data as the first “deadly sin” of statistical analysis. Going back even earlier, Mayer (1971) demonstrated how the correlation between two variables can be distorted if ordinal data was treated at interval level. In contrast, those with a more ‘liberal’ approach see no issues with the use of parametric procedures for ordinal scales and argue that the assumptions for the validity of sampling distributions do not include scale type (Knapp, 1990). Indeed, it is possible to obtain normal distributions for ordinal scales (Thomas, 1982). It should also be acknowledged that the use of non-parametric tests can be more powerful than parametric tests when the data are not normally distributed (Knapp, 1990).

Guidelines for the evaluation of ordinal data have been suggested. Gadermann, Guhn, and Zumbo (2009) suggested the use of ordinal reliability coefficients that are based on the polychoric correlation matrix, rather than the Pearson covariance matrix. This is because the Pearson covariance matrix is based on the assumption that data are continuous; therefore, violation of this assumption can lead to distortion of the covariance matrix. On the other hand, a polychoric correlation estimates the linear relationship between two unobserved continuous variables that are measured using observed ordinal data (Zumbo, Gadermann, & Zeisser, 2007). The polychoric correlation matrix therefore takes into account the ordinal nature of data. On the basis of these arguments, Zumbo et al. (2007) introduced ordinal alpha, which is a coefficient alpha for ordinal data that is derived from the polychoric correlation matrix. They conducted a simulation study comparing ordinal alpha and Cronbach's alpha and found a consistently negative biased estimate of the theoretical reliability with Cronbach's alpha. The negative bias was more evident when the data were negatively skewed. Gadermann et al. (2009) re-analysed the data from Zumbo et al. (2007) and found that ordinal alpha was a suitable estimate of reliability regardless of the number of scale points or the skewness of the distribution. Cronbach's alpha, on the other hand, decreased as the skewness of the scale item increased and as the number of response options decreased. Both Gadermann et al. (2009) and Zumbo et al. (2007) recommended the use of the polychoric correlation matrix and ordinal reliability coefficients when analysing Likert-type or ordinal data.

Although the arguments against the treatment of ordinal data at interval level may be valid, according to Norman (2010) they fail to take into consideration the robustness of parametric tests. "Robustness" in this context refers to the extent to which the test provides the right answer even when assumptions have been violated (Norman, 2010). An issue with those that defend the notion that parametric tests cannot be used on ordinal data is that they tend to ignore the many studies of robustness (Carifo & Perla, 2007, 2008; Norman, 2010). Norman (2010) demonstrated the robustness of Pearson correlations by correlating and comparing Pearson and Spearman coefficients that were based on ranked data. Virtually identical results were found with very high correlations (above 0.9) even with severely skewed data. Moreover, Norman (2010) argued that even though Likert scales are conceptually ordinal and that theoretically the true distance between the response options cannot be guaranteed, this is irrelevant to the analysis. This is because there is no way of verifying or refuting this issue. The analysis can only lead to conclusions about the numbers

themselves but not about differences in the underlying, latent characteristic that are reflected in the Likert numbers.

In an attempt to resolve the debate, Carifo and Perla (2007) discussed what they called “misconceptions, myths and urban legends” that “ordinalists” believe about Likert response options. For instance, the ordinalist view of Likert response options does not differentiate between Likert response options, Likert questions (single items), and Likert scales (group of items) (Carifo & Perla, 2008). These different elements of Likert type data form the root of many of the logical problems that are debated (Carifo & Perla, 2008). There are major differences between a Likert response format and a Likert scale, which need to be acknowledged (Carifo & Perla, 2007). Allen and Seaman (2007) is an example of the misuse of terminologies. In their report, the term “Likert scale” was used to describe both a set of items (correct use) and the response format of a single item. They argued that treating ordinal data as interval may lead to misleading conclusions and provided an example of this using a single item. While a single item with a Likert response format produces ordinal data, Likert-type items that are combined in a scale produce empirical interval data (Carifo & Perla, 2007, 2008). It should be pointed out that the analysis of a single Likert item should be avoided because reliability would be greatly reduced as well as the fact that a single item is not considered a scale (Carifo & Perla, 2007, 2008).

Another misconception that Carifo and Perla (2007) discussed is the issue that data from Likert response formats cannot be analysed using parametric tests. In response to this “myth” they discuss a well-known study by Glass, Peckham, and Sanders (1972) that demonstrated that the F-test when conducting an ANOVA was very robust to violations of the interval data assumption and moderate skewness with no resulting bias. In addition, data from Likert response formats have been shown to be empirically linear and interval at the macro or scale level (Carifo & Perla, 2007). Based on the literature discussed, the “liberal” or intervalist view of Likert scales that parametric tests can be used with Likert data was adopted in the current research.

Chapter 3: Systematic review of treatments for female sexual pain

Introduction

There has been an increase in the number of treatment studies of sexual pain disorders in the past decade, which is evident by the number of reviews in this area (Landry, Bergeron, Dupuis, & Desrochers, 2008; McGuire & Hawton, 2009; Melnik, Hawton, & McGuire, 2012; Stones, Cheong, & Howard, 2005). Stones et al. (2005) reviewed interventions for treating CPP with outcome measures assessing pain and quality of life (QOL). Melnik et al. (2012) reviewed only studies that evaluated interventions for vaginismus. The primary outcome measure was the ability of participants to be able to have sexual intercourse. Secondary outcome measures included QOL, sexual satisfaction, and treatment satisfaction. In 2008, Landry et al. conducted a good in-depth critical review of treatments for PVD and more recently, Flanagan, Herron, O'Driscoll, and Williams (2014) published a systematic review and meta-analysis of psychological treatments for vaginal pain. Both reviews focused on pain and sexual functioning outcomes. All of these reviews, however, have focused on only one type of disorder. The Flanagan et al. (2014) review examined three disorders under the heading of vaginal pain (vulvodynia, vaginismus, and dyspareunia), but only reviewed psychological treatments.

An updated systematic review on the treatment of a broad range of female sexual pain is warranted. Unlike past reviews that have focused on single female sexual pain problems (or pelvic pain), the current review included interventions for all female sexual pain problems, including CPP. The prevalence of sexual pain in women with chronic pelvic pain is high (Verit, Verit, & Yeni, 2006). The individual, social, and economic burden of sexual pain remains significant (Ayling & Ussher, 2008; Gates & Galask, 2001; Xie et al., 2012) and there are diverse treatment options. Although guidelines on treatment have been published (Engeler et al., 2016), a review of the treatments will provide supporting evidence and help clinicians assess which treatments are most efficacious for women with sexual pain problems. Optimal treatment delivered early (soon after diagnosis) may prevent chronicisation of pain and reduce associated sexual, psychological, and relationship distress.

The objectives of this systematic review of the literature were to answer the following key questions: (i) Which treatments for female sexual pain have been evaluated in clinical

studies? (ii) What is the effectiveness of these treatments? (iii) When follow-ups are carried out, are improvements in sexual functioning, satisfaction, or pain maintained?

Method

The guidelines outlined in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement were used (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

Search Strategy

A study protocol was initially formulated and reviewed by experts in the pain and sexual medicine field. Database searches were carried out in PsycINFO, Medline, Web of Science, Embase, CINAHL and The Cochrane Library. The reference lists of all articles that were identified as a result of the searches were also checked for relevant studies that may not have appeared in the databases. The title, abstract, and the introduction of all articles that initially appeared suitable were checked and screened against the inclusion/exclusion criteria. Decisions about whether a given article should be included or excluded and full text retrieval were made jointly with one of the supervisors (CG) .

The searches aimed to identify relevant studies that assessed treatments for female sexual pain. The time period of each search ranged from the start date of each database (PsycINFO: 1887; Medline: 1946; Web of Science: 1970; Embase: 1847; CINAHL: 1981; The Cochrane Library: 1898) to November 30, 2014. Past review papers acted as starting points for searches, with reference lists and key terms checked. The search terms used for each database consisted of a sexual pain term and an intervention term. Sexual pain terms that were searched included “female sexual pain,” “dyspareunia,” “vaginismus,” “sexual pain,” “vulvodynia,” “vestibulodynia,” “pelvic pain,” “vulvar pain,” “gynecologic/gynaecologic pain,” and “vulvar vestibulitis.” Intervention-based terms included “cognitive behaviour/behaviour therapy,” “psychological therapy,” “behaviour/behaviour therapy,” “physical therapy,” “online intervention,” “internet-based,” “biofeedback,” and “vestibulectomy.” Sexual pain terms were grouped or paired with intervention terms and searched with *AND* or *OR* within each database. These search terms were chosen based on key words and headings of papers in this field as well as on previous reviews on sexual pain. In addition, the terms were chosen to reflect all the possible conditions associated with sexual

pain and possible treatments. Some of the terms were adapted to consider American vs English spellings. The specific search fields for each database used for the searched were as follows:

- **PsychINFO:** via EBSCO (“DE” – Descriptor) (All searched under the default field, which searches authors, subject headings, keywords, titles, and abstracts and narrowed by subjectGender: - female; Age groups: 18 years and older)
- **Medline:** via EBSCO (‘MH’ – Exact subject heading; ‘MM’ – Exact major subject heading; ‘DT’ – Drug therapy; ‘TU’ – Therapeutic use; ‘SU’ – Surgery; ‘PX’ – Psychology; ‘TH’ - Therapy) (All searched under the default field, which searches authors, all subject headings, keywords, titles, and abstracts; and narrowed by Sex: Female; Age Related: All Adult: 19+ years)
- **Web of Science:** via Web of Knowledge (all searched under ‘Topic’, which searches the following fields: Title, abstract, keywords, and keywords plus; and “DOCUMENT TYPES: (Article OR Abstract of Published Item)”
- **Embase:** via Ovid (exp – exploded search term; dt – drug therapy; su – surgery; th – therapy; ct – clinical trial; cm – drug comparison; tp – topical drug administration; po – oral drug administration; mp. – multi-purpose/ searches title, original title, abstract, subject heading, name of substance, and registry word fields; af – All fields; ‘/’ - searched as a subject heading; all we searched under “female” [subjects] and “Journal Article” [Publication Types])
- **CINAHL:** via EBSCO (‘MH’ – CINAHL Exact subject heading; ‘MM’ – CINAHL Exact major subject Heading; ‘DT’ – Drug therapy; ‘TH’ – Therapeutic use; ‘SU’ – Surgery; ‘PF’ – Psychosocial factors; ‘DE’ – Drug effects) (All searched under the default field, which searches authors, subject headings, keywords, titles, and abstracts)
- **Cochrane library:** Library (‘MeSH’ – Medical subject headings; All searched within titles, abstracts, and keywords)

Inclusion/Exclusion Criteria

Randomized controlled trials (RCTs), retrospective, prospective, and cohort studies were included in the review. Studies had to report on an intervention, which could include any of the following: CBT, psychological interventions, physical therapies, medical therapies

(pharmacological therapies and surgical procedures), or alternative treatments (e.g., acupuncture, hypnotherapy). Participants must have been female and either already diagnosed with a sexual pain disorder or screened and assessed as having sexual pain. Studies were included if their primary purpose was to evaluate a treatment for female sexual pain regardless of its cause. Criteria for sexual pain disorders included the DSM-IV-TR, (American Psychiatric Association, 2000), ICD-10 (World Health Organization, 2008) and Friedrich's (1987) criteria. Participants in included studies had to be over 18 years of age.

Studies included were required to assess, and report on, pain with sexual activity as one of the treatment outcome measures. Interventions that primarily aimed to treat physical conditions such as vaginal atrophy, endometriosis, and candidiasis were excluded, as were treatment studies involving women with pelvic pain associated with pregnancy or childbirth procedures (e.g., episiotomy). Finally, studies evaluating treatments that are no longer in use (e.g., perineoplasty) were excluded, as were case reports and studies employing qualitative designs.

Quality Assessment

The Cochrane Risk of Bias criteria (Higgins & Green, 2011) were used to assess the level of bias within each study. This is a "domain-based evaluation" whereby critical assessments are made for each of a number of bias domains. This included random sequence generation (biased allocation to interventions), allocation concealment (bias due to inadequate concealment of allocations), blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data (attrition bias), selective reporting (reporting re-specified outcomes), and other types of bias not covered by the criteria.

Results

The search strategy resulted in 65 articles included in this review. Because of the marked heterogeneity of the studies and because the majority lacked a control or comparison group, all of the studies were narratively reviewed. The quality assessment carried out indicated that the majority of the studies reviewed had a high risk of bias related to blinding of the participants (80.3%) and blinding of the outcome assessment (68.1%); 19.7% of the studies also showed a high risk of bias related to incomplete outcome data.

The flow of papers throughout the search process is illustrated in Figure 1 (Appendix B). The treatments were divided into the following categories: Medical Treatments; Surgical Treatments; Physical Therapies; Psychological Therapies; Comparative Treatment Studies; Miscellaneous and Combined Treatments. A summary of the studies is presented in Table 2 (Appendix C). Table 3 (Appendix D) outlines the risk of bias within each study.

Medical Treatments

Medical treatments included topical applications and injections.

Topical Treatments

Seven studies that assessed topical applications used to treat vulvar pain – 1) lidocaine, 2) capsaicin, 3) amitriptyline/baclofen, 4) nifedipine, and 5) cromolyn cream with cutaneous fibroblast lysate – were identified. Lidocaine is a local anaesthetic used to block peripheral neuropathic pain (Rogers, Tang, Madge, & Stevens, 2006). Capsaicin is the molecule found in chilli peppers that causes them to be spicy (Clapham, 1997). It causes the sensation of burning by depolarising afferent neurons. The proposed beneficial mechanism of capsaicin is desensitisation caused by an acute reaction mediated by neuropeptides (Steinberg, Oyama, Rejba, Kellogg-Spadt, & Whitmore, 2005). Amitriptyline is a tricyclic antidepressant which is predicted to induce analgesia by blocking sodium channels similar to local anaesthetics (Rogers et al., 2006). Baclofen is a central nervous system depressant commonly used to treat muscle spasms (Baclofen, 2011). Nifedipine is a calcium channel blocker and is used to treat angina and hypertension (Nifedipine, 2016). Finally, cromolyn is an anti-inflammatory medication and blocks the release of mast cells (Nyirjesy et al., 2001).

In a prospective study, Zolnoun et al. (2003) assessed the effectiveness of nightly application of 5% lidocaine ointment, a local anaesthetic, on daily pain ratings and intercourse-related pain among 61 women diagnosed with VV. After seven weeks, 76% of the women reported being able to have intercourse, compared with 36% before treatment, a significant increase. Only 30 of the 61 women returned the 6-month follow-up questionnaire; of these, 77% reported ongoing use of the lidocaine. Twenty percent who had stopped the treatment reported sustained improvement in their symptoms and their ability to have intercourse. Some patients (number not specified) experienced burning after applying the ointment.

Two studies evaluated capsaicin in samples of women with VV (Murina, Radici, & Bianco, 2004; Steinberg et al., 2005). In a prospective uncontrolled trial, 33 women with VV were treated with topical capsaicin (0.05%); 19 patients (59%) reported improvement in symptoms of dyspareunia, burning, and irritation after eight weeks of treatment (Murina et al., 2004). In a retrospective chart review, Steinberg et al. (2005) tested capsaicin cream (0.025%) in a sample of 52 women with VV; after 12 weeks, significant improvements in dyspareunia and in responses to the Kaufman touch test (evaluating discomfort) were observed. A disadvantage of capsaicin is the severe burning sensation experienced even after application of local anaesthetic cream, which limits its practicality (Murina et al., 2004; Steinberg et al., 2005).

In a retrospective study of 38 women with PVD, Nyirjesy et al. (2009) examined the effects of amitriptyline 2%/baclofen 2% cream on vestibular pain. After a median follow-up of 33 weeks, 11 (29%) of patients reported little or no improvement, 7 (18%) moderate improvement, and 20 (53%) much improvement. Eleven (29%) reported localized burning from the treatment. Although there were significant reductions in pain during intercourse and improvement in lubrication, there were no changes in reported frequency of intercourse, sexual desire, or sexual satisfaction.

One double-blind placebo-controlled study investigated the effectiveness of topical application of nifedipine (0.2% or 0.4%) in 30 women with PVD (Bornstein, Tuma, Farajun, Azran, & Zarfati, 2010). Reports of pain during intercourse, pain from speculum insertion, and pain assessed by the cotton swab test were lower after six weeks of treatment compared with pretreatment in all three groups. Improvements were maintained at three-month follow-up but in none of the comparisons was the effectiveness of nifedipine superior to that of placebo.

The effectiveness of cromolyn (4%) cream in 26 women with VVS was assessed in a prospective, double-blind trial (Nyirjesy et al., 2001). After three months of treatment, although symptoms of irritation, burning, and dyspareunia had improved, there were no statistically significant differences between the active treatment and the placebo groups.

In a double-blind, placebo-controlled crossover trial, Donders and Bellen (2012) studied the effects of treatment with cutaneous lysate skin cream in 30 women with PVD. During the first 12 weeks, use of the active cream resulted in a significant reduction in pain during sexual activity compared with placebo; the reduction in pain ranged from 20-30%.

Injections.

Botulinum toxin type A (Botox) and nerve blockades were the two main types of injections investigated, with an additional study using enoxaparin (Farajun, Zarfati, Abramov, Livoff, & Bornstein, 2012). Botox influences pain by reducing muscle hyperactivity through a number of different pain mechanisms, including blocking presynaptic cholinergic synapses and the release of neurotransmitters involved in pain perception (Dressler & Saberi, 2005). In the studies identified, Botox (between 20-400 units) was injected either into the levator ani muscles (Bertolasi et al., 2009; Jarvis, Abbott, Lenart, Steensma, & Vancaillie, 2004; Yoon, Chung, & Shim, 2007), the bulbospongiosus muscles (Abbott, Jarvis, Lyons, Thomson, & Vancaillie, 2006; Hillis, Marchbanks, & Peterson, 1995; Peterson, Giraldi, Lundvall, & Kristensen, 2009; Shafik & El-Sibai, 2000), the puborectalis and pubococcygeus muscles (Abbott et al., 2006), or painful vulvar areas identified by touch with a cotton swab (Dykstra & Presthus, 2006). The majority of the studies included women with vulvar pain problems such as vulvodynia; three studies included women with CPP not limited to vulvar pain (Abbott et al., 2006; Jarvis et al., 2004; Nesbitt-Hawes et al., 2013). Botox treatment resulted in improved vaginal muscle resistance (Abbott et al., 2006; Bertolasi et al., 2009; Ghazizadeh & Nikzad, 2004), enhanced ability to have intercourse (Pelletier et al., 2011; Shafik & El-Sibai, 2000; Yoon et al., 2007), reduced dyspareunia (Jarvis et al., 2004), improved overall sexual function (Peterson et al., 2009), improved quality of life (Dykstra & Presthus, 2006; Jarvis et al., 2004; Pelletier et al., 2011), and reduced pain overall (Bertolasi et al., 2009; Ghazizadeh & Nikzad, 2004; Jarvis et al., 2004; Pelletier et al., 2011; Shafik & El-Sibai, 2000; Yoon et al., 2007). In Peterson et al.'s (2009) placebo-controlled study, however, there were no significant differences between Botox treatment and placebo.

Two studies examined pudendal nerve blockade. In a prospective pilot study, Rapkin et al. (2008) investigated the effectiveness of using multilevel anaesthetic injections to target small nerve fibres that supply the vestibule, the pudendal nerves, and the sacral 2-4 dorsal root ganglia that subserve the pudendal nerve in 27 women with vestibulodynia. There were five treatment sessions every 2-3 weeks. At posttreatment, a significant improvement in pain with intercourse was found. Significant improvements were also found in vestibular pain from baseline to the last follow-up (4-6 months posttreatment). A more recent uncontrolled pilot study investigated the use of multilevel local anaesthetic nerve blockade for the treatment of generalized vulvodynia (McDonald & Rapkin, 2012). Thirty-two women entered the study and 26 women completed the five treatment sessions and a follow-up session 2-3

months after treatment ended. Although there were no significant changes on the pain domain of the FSFI, in responses on a global satisfaction question (“What is the average percent improvement in your pain with intercourse?”), the mean improvement was 56%; 61% of participants stated at follow-up that sexual intercourse was “enjoyable.”

In a randomized controlled trial, the effectiveness of enoxaparin (an anticoagulant) in treating PVD was assessed (Farajun et al., 2012). Forty women with severe PVD self-administered daily injections of either 40 mg enoxaparin or the same volume of saline solution for 90 days. Women were assessed at pretreatment, posttreatment, and three months after treatment. Compared with placebo, the enoxaparin-treated women showed significantly greater improvement in pain, pain during intercourse, and vestibular sensitivity at posttreatment and at the three-month follow up.

Critical review – outcome studies on medical treatments.

Most early studies that evaluated topical treatments were uncontrolled prospective trials or retrospective studies of women who had previously received treatment. More recently, some double-blind placebo-controlled trials in this area have been carried out (Bornstein et al., 2010; Donders & Bellen, 2012). Outcome studies on Botox and on pudental nerve blockage were also of mixed quality; only a small number of these were placebo-controlled (Farajun et al., 2012 on enoxaparin; Abbott et al., 2006; Peterson et al., 2009 on Botox).

Surgical Treatments

Surgical treatments included vestibulectomy, modified vestibulectomy, and laparoscopic surgeries. In vestibulectomy, the hymenal ring is usually removed and/or sensitive areas in the vestibular (or the entire vestibular) are excised and tissues from the posterior fourchette down to the perineum are also removed (Goldstein, Klingman, Christopher, Johnson, & Marinoff, 2006; Goldstein, 2010). Five retrospective studies were found that evaluated vestibulectomy. The findings suggested that vestibulectomy can significantly reduce vulvar pain (Bergeron, Bouchard, Fortier, Binik, & Khalife, 1997; Bohm-Starke & Rylander, 2008; Lambert et al., 2012). Follow-up varied from one to 12 years. No major complications of the surgery were reported; “minor” complications were decreased lubrication, hematomas, postoperative bleeding, infection, and Bartholin cysts,

reported by 1-27% of patients (Bergeron et al., 1997; Bohm-Starke & Rylander, 2008; Goldstein et al., 2006; Traas et al., 2006).

In modified vestibulectomy, only tender areas within the vestibule are removed and the excision is limited to the posterior fourchette of the vestibular area (Goetsch, 1996). Eight studies were identified that evaluated modified vestibulectomy. Seven were retrospective (Eva, Narain, Orakwue, & Luesley, 2008; Goetsch, 1996, 2008; Kehoe & Luesley, 1996; Lavy, Lev-Sagie, Hamani, Zacut, & Ben-Chetrit, 2005; Rettenmaier, Brown, & Micha, 2003; Tommola et al., 2011), one was an observational case-control study (Tommola, Unkila-Kallio, & Paavonen, 2012), one was an observational study (Goetsch, 2007), and one was prospective (Kehoe & Luesley, 1999). Follow-up varied from 6 months to 14 years. One study evaluated modified vestibulectomy in conjunction with a modified Fenton's procedure (Kehoe & Luesley, 1996, 1999), which involves the removal of scar tissue resulting from perineal trauma or tear (Chandru, Nafee, Ismail, & Kettle, 2010).

In Goetsch's (1996) study, 10 (83%) participants reported complete resolution of vestibular tenderness. Five women (42%) described having some degree of vaginismus after surgery; for some, this resolved without treatment while others needed desensitization therapy with vaginal dilators (exact number of women not reported). Follow-up ranged from six months to six years. In a later observational study, Goetsch (2007) evaluated surgery combined with "muscle therapy" in 111 women who had dyspareunia. At three-month follow-up, 24% reported less pain during intercourse, 9% no change, and 3% were worse. In another observational study, Goetsch (2008) followed up 133 women who had undergone modified superficial vestibulectomies; 119 returned follow-up questionnaires and of these, 68% reported that they no longer had pain during intercourse, 24% said that the pain had lessened, 8% reported no improvement, and 2% were worse. In a long-term follow-up study, Tommola et al. (2011) found that 69.2% of their sample of 57 patients who attended for follow-up reported a 50% or greater decrease in dyspareunia following surgery. Posterior vestibular tenderness following surgery was absent in 34 (64.2%) women and "mild" in 11 (20.8%). Anterior vestibular tenderness was absent in 15 (28.3%) and "mild" in 14 (26.4%) women. The average length of follow-up was 36 months.

In four studies, response to surgery was defined as complete (return to normal, non-painful intercourse), partial (return to "normal" sexual intercourse; even though occasional dyspareunia existed, it did not prevent sexual activity), and non-responsive (none or minimal improvement) (Kehoe & Luesley, 1996, 1999; Lavy et al., 2005). The follow-up periods in these studies ranged from two months to ten years. In the retrospective study discussed above

by Tammola et al. (2011), of 54 women, 19 (35.2%) reported complete response (cured by operation), 30 (55.6%) partial response (still had some complaints), and 5 (9.3%) no response (same or worse than before operation). Of the sexually active women, 7 (14%) reported no dyspareunia and 29 (58%) reported at least half of occasions of intercourse as painless; however, persistent dyspareunia was reported by 10 (20%) women. In an observational case-control study (Tammola et al., 2012), 66 women, all treated initially with conservative treatment, were followed up after treatment for VV. Thirty-nine women opted for modified posterior vestibulectomy because of insufficient relief from conservative management (details of conservative treatment not described). Dyspareunia decreased significantly in both surgery and conservative treatment groups from baseline to the follow-up visit. Complete response was reported by 13/36 (36.1%) women from the surgery group and 7/27 (25.9%) women from the conservative treatment group. Partial response was reported by 19 (52.8%) and 17 (63.0%) women, respectively, and no response by 4 (11.1%) and 2 (7.4%) women, respectively. Differences between the two groups, including in sexual wellbeing, were not statistically significant.

One recent study followed up 30 women three years after they had undergone vulvar vestibulectomy for PVD (Brokenshire, Pagano, & Scurry, 2014). Twenty-nine of the 30 patients were deemed to have had a good response at three months post-surgery; at the three-year follow-up, 28 women reported complete improvement (no dyspareunia), one some improvement, and one patient reported no change.

Postoperative complications following vestibulectomy were reported in a number of studies and included postoperative bleeding (Tammola et al., 2011) and postoperative pain (Lavy et al., 2005).

Baggish (2012) prospectively evaluated 502 women that participated in a structured medical regimen for VV. Each patient was first treated with a conservative treatment protocol that included tricyclic antidepressants or gabapentin and a low-oxalate diet recommended with a prescription of calcium citrate (either 400 mg three times daily or 1200 as a single daily dose). Patients also received biofeedback from a physical therapist. Surgery consisted of either vestibulectomy only or vestibulectomy and excision of the Bartholin glands. Participants were followed up for a minimum of 12 months. Ninety-eight (20%) women continued on the conservative treatment program with tolerably low pain during intercourse. The other 404 women (80.5%) underwent surgery. Of the 234 that underwent vestibulectomy with Bartholin gland removal, 228 (97%) reported pain-free intercourse. One hundred and

seventy women underwent vestibulectomy alone and of these, 161 (95%) reported pain-free intercourse.

One RCT investigated laparoscopic uterine nerve ablation (LUNA). Palomba et al. (2006) compared LUNA and vaginal uterosacral ligament resection for the treatment of 80 postmenopausal women with CPP. A patient was defined as “cured” if she no longer had CPP or had pain not requiring medical treatment after 6 and 12 months post-surgery. The cure rate was not significantly different between the two groups at 6 months after surgery. The severity of CPP and deep dyspareunia significantly reduced at 6 and 12 months post-surgery, with no significant differences between the two treatments.

Critical review – outcome studies on surgical treatments

Almost all of the early studies that evaluated vestibulectomy and modified vestibulectomy employed retrospective and uncontrolled designs. There was a very large range of follow-up periods in these studies, with some follow-ups as short as six months post-surgery (Lavy et al., 2005). Finally, in comparison with research on some of the other treatments reviewed (e.g., physical therapies and psychological therapies) outcome measures assessed in surgical treatment studies were more likely to be limited to pain and other physical indices.

Physical Therapies

Studies that assessed physical therapies were grouped into the following categories: desensitization with dilators, electrical stimulation, electromyographic biofeedback, and combined physical therapy programs.

Desensitization with Dilators

Two prospective studies evaluated the use of vaginal dilators alone. (Murina, Bernorio, & Palmiotto, 2008a) assessed the effectiveness of vaginal dilators among 15 women diagnosed with vestibulodynia who had all received previous therapies e.g., transcutaneous electrical nerve stimulation (TENS), vestibular infiltrations, biofeedback, and pelvic floor exercises. After eight weeks of treatment with dilators, there were significant improvements in dyspareunia and sexual functioning compared with pretreatment. Schnyder,

Schnyder-Lüthi, Ballinari, and Blaser (1998) compared the effectiveness of two forms of desensitization exercises in treating 44 women with vaginismus: “*in vivo*” (where the physician introduced the dilator) and “*in vitro*” (the physician provided verbal instructions for introducing the dilator and the patients inserted the dilator themselves). At the end of treatment (6-7 therapeutic sessions plus homework), 43 (97.7%) of the women were able to have sexual intercourse, although 22 (50%) still experienced some pain. No significant differences were found between the *in vivo* and *in vitro* groups. At follow-up (mean 10 months posttreatment; range 6-22 months), 18 (50%) women reported that the vaginismus had completely disappeared and 17 (47.7%) reported that it had improved. The majority of patients also rated their sexual desire (14/35.9%) and orgasmic capacity (7/17.9%) as having improved. This suggests that exposure using vaginal dilators alone is effective at improving sexual functioning regardless of whether is partnered sexual activity is occurring or not.

Electrical Stimulation

Three prospective studies (deBernardes, Marques, Ganunny, & Bahamondes, 2010; Fenton, Palmieri, Boggio, Fanning, & Fregni, 2009; Murina et al., 2008b) evaluated electrical stimulation treatments. Electrical stimulation induces analgesia and relieves pain by activating pain inhibitory pathways as well as low-threshold peripheral afferents, which inhibit nociceptive transmission to the central nervous system (Jones & Johnson, 2009).

In an uncontrolled study, Nappi et al. (2003) investigated the use of electrical stimulation in the vulvar vestibular area in 29 women with either dyspareunia (n = 20) or vaginismus (n = 9). Treatment followed a protocol of 20 minutes of stimulation once a week for 10 weeks. At posttreatment, the contractile and resting ability of the perineal floor muscles had significantly improved and the current intensity tolerated at the vestibular area had significantly increased. Significant improvements were also found in pain and sexual functioning at posttreatment compared with pretreatment.

In a randomized, placebo-controlled trial, Murina et al. (2008b) evaluated TENS in the management of 40 women with vulvodynia. A total of 20 treatment sessions were held for women in both groups. At posttreatment, TENS was more effective than placebo at improving sexual function, reducing pain, and reducing dyspareunia at posttreatment. At the 3-month follow-up, improvements in the TENS group were maintained. In a more recent study, Murina, Graziottin, Felice, Radici, and Tognocchi (2013) assessed the effect of TENS in combination with either palmitoylethanolamide (PEA) + transpolydatin, an endogenous

fatty acid amide, or placebo, in 20 women with vulvar pain. All of the women received sessions of TENS (mean 26.7 sessions). Although there were no differences between the PEA and placebo groups, dyspareunia scores had reduced significantly in both groups at posttreatment. No follow-up assessment was carried out.

Finally, in a small controlled study, Fenton et al. (2009) compared transcranial direct current stimulation (tDCS) with sham treatment in reducing CPP. Seven women with refractory CPP were randomized to receive either active or placebo tDCS. Patients were then crossed over to receive the alternative treatment. Pelvic pain scores were significantly lower two weeks after tDCS treatment compared with sham therapy, but intercourse-related pain increased significantly with the active treatment compared with placebo.

Electromyographic Biofeedback (EMG)

It has been suggested that hypertonicity of the pelvic floor muscles (PFMs) is partly responsible for aggravating vulvo-vaginal pain (Landry et al., 2008). EMG biofeedback aims to destabilize the PFMs (Glazer, Rodke, Swencionis, Hertz, & Young, 1995), which in turn is expected to resolve the pain. Three studies investigated EMG biofeedback in women with vestibulodynia (Glazer, 2000; Glazer et al., 1995; McKay et al., 2001). Glazer and colleagues (Glazer, 2000; Glazer et al., 1995) evaluated a standardized protocol consisting of resting baseline, muscle contraction periods, and periods that alternated between resting and contracting. McKay et al. (2001) used a similar protocol consisting of an initial assessment of the PFMs. In all of these three studies, women were instructed to use a portable EMG at home. Treatment lasted a mean of 8.7 months in one study (Glazer, 2000) and 16 weeks in the study by Glazer et al. (1995); duration was not reported in the study by McKay et al. (2001).

Glazer (2000) and Glazer et al. (1995) found significant reductions in vulvar and sexual pain at follow-up; sexually active patients reported a significant increase in intercourse frequency. In the study by McKay et al. (2001) 15 (51.7%) of the 29 women reported significantly reduced introital tenderness and of this group, 14 (93.3%) were able to resume intercourse without discomfort. Five women (17.2%) reported no improvement in symptoms and none of these resumed sexual intercourse.

Combined Physical Therapy Programs

Combined physical therapy programs are those comprising a combination of physical therapies, including EMG biofeedback, electrical stimulation, vaginal dilators, and education (e.g., on the role of the PFM's in maintaining pain). Three studies that assessed physical therapy programs were identified.

In a retrospective study, Bergeron et al. (2002) assessed the effectiveness of physical therapy in improving painful intercourse and sexual function in a sample of 35 women diagnosed with VV. Physical therapy comprised manual techniques (e.g., stretching), EMG feedback, electrical stimulation, and home exercises. There were seven sessions of treatment and the mean length of treatment follow-up was 15.8 months. Results indicated a complete or "great" improvement for 51.4% of participants, moderate improvement for another 20.0%, and little to no change for the remaining 28.6%. There was a significant decrease in pain experienced not only during sexual intercourse, but also during gynaecological examinations; increases in intercourse frequency and levels of sexual desire and arousal were also reported.

Goldfinger et al. (2009) prospectively examined the effectiveness of a comprehensive pelvic floor physical therapy (PFPT) intervention in treating pain and improving sexual and psychological functioning in 13 women with PVD. The PFPT intervention comprised eight sessions of intravaginal manual techniques, EMG, vaginal dilators of increasing diameters, and home exercises. The women were assessed before treatment, within one month after treatment, and between three and four months after treatment using gynaecological examinations, face-to-face interviews, and standardised questionnaires. Significant reductions in all pain measures, including pain during intercourse, were found at posttreatment assessments. Significant improvement also occurred for overall sexual function, but not for specific components of sexual function (desire, arousal, lubrication, and orgasm). No significant changes were found in depression and anxiety scores or in intercourse frequency. Treatment was reported as successful ("complete cure" or "great improvement" in vulvar pain) for 10 (77%) participants and unsuccessful for 3 (23%) women.

In an open, randomized study, Heyman, Öhrvik, and Leppert (2006) evaluated the effects of dorsal stretching of pelvic structures in 50 women with CPP who were randomized to either a treatment (distension) ($n = 25$) or control group ($n = 25$). Distension of painful structures was done using the physician's index finger. At posttreatment assessment 2-3 weeks after the second session, compared with controls, the treatment group had greater reductions in the intensity, frequency, and duration of pelvic pain, painful intercourse, mental fatigue, and depression.

Critical review – outcome studies on physical therapies

This category comprised a heterogeneous group of therapies and the methodological quality of the studies was similarly quite mixed. There were three controlled studies identified (Heyman et al., 2005; Murina et al., 2008b; 2013) but all of the other studies used uncontrolled prospective designs. Some of the studies reviewed also had very small sample sizes and few involved any long-term follow-up.

Psychological Therapies

Psychological therapies were divided into cognitive behaviour therapy (CBT) approaches and other psychological interventions. CBT is a psychological therapy which aims to increase an individual's pain control and ultimately, reduce pain in the sexual situation (Ter Kuile & Weijnenborg, 2006). Pain and sexual coping strategies are practiced, which are expected to reduce muscle contraction in the pelvic floor and in turn lead to the promotion of lubrication during sexual activity (Ter Kuile & Weijnenborg, 2006). Other components of CBT include cognitive restructuring (to adjust maladaptive pain/sexual cognitions), gradual desensitization, and relaxation techniques (Engman et al., 2010; Kabakçi & Batur, 2003). Although a psychological therapy, CBT programs commonly include physical therapy techniques such as vaginal dilation (carried out by the patient) and other components such as sensate focus. Sensate focus is a technique developed by Masters and Johnson (1970), which comprise a series of touching exercises engaged in by couples, designed to increase sexual awareness and communication between partners.

Cognitive Behaviour Therapy Approaches

Corsini-Munt, Bergeron, Rosen, Mayrand, and Delisle (2014) conducted a pilot study of a novel cognitive-behavioural couple therapy for women with PVD. Eight couples completed the 12-session manualized intervention, which included psychoeducation about pain, communication skills training, and mindfulness, but also utilized an acceptance and commitment approach. The primary outcome measure was women's pain intensity during intercourse. There was a significant decrease in dyspareunia from pre- to post-treatment and also improvements in sexual functioning and sexual satisfaction for both partners (no follow-up assessment was reported). Improvements in pain-related cognitions, anxiety, and

depression were also evident for both partners. This was the first treatment study that systematically included the partner.

In a prospective open trial, Ter Kuile and Weijenborg (2006) investigated whether CBT was effective for 76 women with VVS. A total of 12 2-hour treatment sessions over a period of six months took place, with six to eight women participating in each group. The sessions comprised education about pain in relation to anxiety, information about muscle contraction as a consequence of pain and fear of pain, and information about sexuality. Specific information was given regarding how pain or the thought of pain resulting from VVS can affect sexual arousal and lubrication and sexual desire. Training in coping, self-statements, and cognitive restructuring was also provided. Progressive muscle relaxation, suggestive relaxation, abdominal breathing, and vaginal dilation by insertion of one or two fingers (by the women themselves or by the partner) were practiced. Women completed the exercises alone in the first half of the program, with partners becoming more involved in the second half of the program, which focused on general communication and sensate focus exercises. Intercourse was eventually reintroduced in a step-by-step fashion. Women were assessed one week and three months after treatment. Significantly lower levels of pain during intercourse were reported at one week posttreatment, as well as reductions in sexual dissatisfaction, vestibular pain, and vaginal muscle tension. Significantly higher scores for perceived pain control were observed one week posttreatment compared with baseline.

Engman et al. (2010) retrospectively assessed the “long-term coital behaviour” of 59 women treated with a CBT program for superficial coital pain and vaginismus. The women were on a wait-list for an average of three months before starting CBT treatment, which consisted of either weekly or bi-weekly sessions of systematic desensitization, with stepwise exposure to the penetrative situation and concurrent relaxation of the PFMs. Participants required an average of 14 (8-26) treatment sessions (treatment ended when individual goals had been reached). Successful therapy was measured as the ability to have intercourse without pain. Forty-four women returned the treatment evaluation questionnaire (74.6% response rate). The average follow-up was 39 months after treatment (range 16-79). At follow-up, a majority (61%) rated their ability to have intercourse without pain as 6 or higher (on a scale from 0–10), and 61% rated their ability to enjoy intercourse as 6 or higher (on a scale from 0–10). The proportion of women with positive treatment outcome at follow-up ranged from 81% (able to have intercourse) to 6% (able to have pain-free intercourse). A large proportion of women had reached their individualized goals [intercourse without pain: 30 (71%); intercourse without fear: 28 (80%); ability to enjoy intercourse: 26 (63%);

becoming pregnant: 17 (77%)]. There was also an increase from assessment to follow-up in self-worth “as a sex partner,” “as a woman,” and “as a human being.” However, despite being called “CBT,” most of the program consisted of behaviour therapy techniques (e.g., systematic desensitization and relaxation of the PFMs), with little description of the cognitive therapy techniques used.

In an RCT, Masheb, Kerns, Lozano, Minkin, and Richman (2009) compared CBT versus supportive psychotherapy (SPT) in 50 women with vulvodynia. Women received either 10 weekly 60-minute sessions of CBT or SPT. The SPT used was non-directive and controlled for the specific behavioural interventions in CBT. Forty-two women completed the 10-week treatment sessions and 47 completed 1 year-follow-up assessments. At posttreatment participants in both groups had statistically significant improvements in self- and physician-reported pain severity, sexual function, depression, and pain anxiety. CBT resulted in significantly greater improvements in physician cotton-tip measures of pain severity from pre- to post-treatment, but the effect size was not significant relative to SPT. CBT also resulted in significant pre- to posttreatment improvements in sexual function and pain during sexual intercourse relative to SPT. At one-year follow up (n = 47) improvements were maintained in both groups.

In a randomized waiting-list controlled trial, van Lankveld, Everaerd, and Grotjohann (2001) evaluated the use of cognitive-behavioural bibliotherapy (CBB) with minimal therapist support. This study involved couples with a number of different sexual dysfunctions; only the results related to women with dyspareunia and vaginismus are discussed here. Twenty couples with a sexual pain problem received bibliotherapy (12 vaginismus, 8 dyspareunia) and 35 were allocated to the waiting-list control group (17 vaginismus, 18 dyspareunia). CBB lasted 10 weeks, followed by a 10-week follow-up period. Couples in the CBB group were given a treatment manual that consisted of a step-by-step program of individual and partner exercises, using a sensate focus approach. At posttreatment, for women with vaginismus, the CBB group had greater improvement than the controls in sexual intercourse frequency, vaginismus, anorgasmia, and self-esteem as a sexual partner. For women with dyspareunia, CBB was only effective in improving sexual intercourse frequency and self-esteem as a sexual partner and these women reported more complaints of vaginal discomfort with CBB. At the 10-week follow-up, these differences were maintained. Overall, the findings suggested that CBB may be more effective for women with vaginismus than women with dyspareunia.

In another randomized wait-list controlled trial, therapist-aided exposure was evaluated as a treatment for 70 women with lifelong vaginismus and their partners ter Kuile, Melles, de Groot, Tuijnman-Raasveld, and van Lankveld (2013). The intervention involved graded exercises using dilators or fingers, verbally “directed” by the therapist, and homework exposure assignments (alone and involving the partner). Systematic assessment carried out included daily diaries, validated questions on sexual functioning and distress, and physical examination. Seven participants dropped out of the study before the 12-week assessment. Treatment was associated with clinical improvement in pain during intercourse, as well as in vaginismus, coital fear, and sexual distress. Thirty-one out of 35 patients in the active treatment group reported having had sexual intercourse at posttreatment vs. four out of 35 in the wait-list control group.

Other Psychological Interventions

In a retrospective study, Ben-Zion, Rothschild, Chudakov, and Aloni (2007) examined the effectiveness of surrogate partner therapy compared to traditional couples therapy for women with vaginismus. Sixteen patients who had been treated with their partner (traditional couples therapy) were compared with 16 patients who underwent therapy with a male surrogate partner. The first stage of treatment involved dilators and tampon or finger insertions. The second stage involved joint sensate focus exercises with the partner or surrogate as part of a progression towards vaginal penetration. All 16 women in the surrogate group achieved successful pain-free sexual intercourse, compared to 12 in the couples therapy group. One patient from the couples therapy group reported no change, another reported being much worse, and two women described mildly positive changes. An implication of this is that single women with sexual pain can potentially engage in, and benefit from, sensate focus exercises without the need to be in a relationship.

Brotto, Sadownik, and Thomson (2010) prospectively investigated the effectiveness of three one-hour gynaecologist-led educational seminars on psychological symptoms and sexual health among 29 women with PVD. The overall goal of the seminars, each involving 4-8 women, was to disseminate accurate information about PVD and there were opportunities for participants to ask questions as well as share experiences with other group members. There were significant improvements in sexual functioning from pre- to posttreatment assessments that were maintained at the 6-month follow-up. Significant improvements were also seen in psychological symptoms, including sexual distress, depression, anxiety, hostility,

paranoid ideation, psychoticism, and somatization, but no significant improvements in sexual pain scores were found at either posttreatment or follow-up.

Critical review – outcome studies on psychological therapies

Overall, the methodological quality of the outcome studies on psychological therapies, particularly those on CBT, was high. There have been a number of RCTs conducted (e.g., Masheb et al., 2009; ter Kuile et al., 2013; van Lankveld et al., 2001). Many of the studies also assessed a broad range of variables e.g., self-esteem as a sexual partner; (van Lankveld et al., 2001) and coital fear (ter Kuile et al., 2013), as well as pain and sexual activity.

Comparative Treatment Studies

Most of the studies reviewed above only investigated one type of treatment, without making comparisons with other treatment types. Five studies met our criteria that compared different types of treatment (Bergeron et al., 2001; Bergeron, Khalifé, Dupuis, & McDuff, 2016; Bergeron, Khalife, Glazer, & Binik, 2008; Bohm-Starke, Brodda-Jansen, Linder, & Danielsson, 2007; Danielsson, Torstensson, Brodda-Jansen, & Bohm-Starke, 2006; Foster et al., 2010).

Bergeron et al. (2016) conducted a randomized trial comparing group CBT therapy with a topical steroid for women with dyspareunia. Ninety-seven women were randomly assigned to one of the two treatments and assessed at pretreatment, posttreatment, and six-month follow-up using validated measures of pain, psychological and sexual functioning, structured interviews, and a gynaecological examination. Women in both treatment groups reported statistically significant reductions in pain (at posttreatment and at six-month follow-up), but the women in the group CBT condition had greater improvements in pain at six-month follow-up and higher treatment satisfaction than those in the topical steroid group.

In an earlier RCT, Bergeron et al. (2001) randomised 78 women with dyspareunia to either group cognitive behavioural therapy (GCBT), sEMG biofeedback, or vestibulectomy. Biofeedback involved self-insertion of a small single-user sEMG sensor into the vagina involving phasic contractions and rest periods; participants in this group received eight 45-minute sessions over a 12-week period. GCBT consisted of two-hour group sessions with 7 to

8 women per group, and included education and information about vulvar pain, sexual anatomy, progressive muscle relaxation, abdominal breathing, Kegel exercises, vaginal dilation, distraction techniques, coping self-statements, communication skills training, and cognitive restructuring. Participants from all three groups reported significant reductions on all pain measures at posttreatment and six month follow-up. At posttreatment and at the 6-month follow-up, vestibulectomy was significantly more successful at reducing vestibular pain than sEMG and GCBT. Vestibulectomy was also significantly more effective at reducing intercourse-related pain at posttreatment and 6 month follow-up than sEMG. All three treatments were equally effective at improving sexual function and psychological adjustment. Participants were followed up after another 2.5 years, and reassessed using the same procedures as in the original study (Bergeron et al., 2008). Women had significantly less pain at 2.5 years compared to the six-month follow-up and vestibulectomy participants again had significantly lower vestibular pain levels than sEMG and GCBT participants. The results also indicated that vestibulectomy was significantly more effective than sEMG at reducing pain during intercourse at the 2.5 year follow-up. No further improvements were found on the sexual function measures, which did not change between six months and 2.5 years.

In another RCT, Danielsson et al. (2006) evaluated EMG biofeedback and topical lidocaine gel as a treatment for 46 women diagnosed with VV. Biofeedback was carried out with home training exercises and computerized assessments of the PFMs. Three biofeedback training sessions were arranged across the four-month study period. Nine of the 46 women dropped out. Both treatment groups showed significantly improved values for vestibular pain thresholds, QoL measurements, sexual functioning, and sexual pain at the 12-month follow-up, with no between-group differences found.

Foster et al. (2010) evaluated lidocaine cream (5%) and/or 25 mg. desipramine tablets compared with placebo as a treatment for 133 women with PVD. There were four treatment groups: placebo tablets–placebo cream, desipramine tablets–placebo cream, placebo tablets–lidocaine cream, and desipramine tablets–lidocaine cream. At week 12, improvements in pain, psychological wellbeing, and sexual satisfaction were found in all groups. Desipramine alone and lidocaine alone were not superior to placebo. Improvements were also found in the cotton-swab test and in pain with intercourse across all treatment groups. Across all of the outcome measures, one measure - sexual satisfaction - improved with desipramine compared with placebo. The highest drop-out rates as well as the most significant side-effects (e.g., dry mouth, hot flushes, dizziness or light-headedness) were found in the desipramine group.

Critical review – outcome studies on comparative treatments

All but one of the five comparative treatment studies was carried out in the last decade and perhaps reflecting this, the methodological quality of these studies was good. All of the five studies identified used randomized controlled designs. Outcome data were comprehensively reported and one of the studies (Bergeron et al., 2008) was a long-term follow-up study undertaken 2.5 years after the initial treatment (Bergeron et al., 2001).

Miscellaneous and Combined Treatments

Miscellaneous treatments identified include acupuncture (Curran, Brotto, Fisher, Knudson, & Cohen, 2010; Danielsson, Sjöberg, & Östman, 2001) and hypnosis (Pukall et al., 2007). Other studies combined different treatments e.g., topical treatments and surgery (Har-Toov, Militscher, Lessing, & Abramov, 2001; Pagano, 1999; Spoelstra, Dijkstra, van Driel, & Weijmar Schultz, 2011; Ventolini, Barhan, & Duke, 2009; Weijmar Schultz et al., 1996).

Curran et al. (2010) assessed eight women with PVD who received 10 acupuncture sessions. After 10 1-hour treatment sessions, the only significant improvement regarding pain-related measures was for pain during manual genital stimulation and cognitions related to helplessness. No significant improvements in the intensity of pain during sexual intercourse, ability to have intercourse, emotional well-being, self-confidence, restful sleep, or energy were observed, although the authors acknowledged that the small sample size limited conclusions that could be drawn.

Pukall et al. (2007) conducted a pilot study to investigate the effectiveness of hypnosis as a treatment for VVS. Patients were initially screened using the Harvard Group Scale of Hypnotic Susceptibility, which assessed response to hypnosis. Women were included if they scored in the moderate-high range in hypnotic susceptibility. The six hypnosis therapy sessions included suggestions related to relaxation, pain control and reduction, and sexual pleasure. Significant improvements from baseline to one- and six-month follow-up were found on measures of pain during cotton-tip palpation, intensity, unpleasantness, and frequency of pain during intercourse, and frequency of pain during non-coital activities. Satisfaction and perceived improvements did not significantly differ between the one and six month follow-ups and overall ratings were reported as “average.”

In an early uncontrolled trial, Pagano (1999) investigated a management protocol as a treatment for 230 women with PVD, first involving simple local measures such as recommending lubricant use during intercourse, then treatment of Candida for those who were Candida-positive, and amitriptyline or carbamazepine for women who were Candida negative. Amitriptyline had positive effects in 60% of women and Carbamazepine carbamazepine in 13% of women. For patients not responding to any of the above measures, surgical vestibulectomy was performed (n = 22) and 20 women (91%) were said to experience “significant improvement.”

Har-Toov et al. (2001) investigated the effect of treating vaginismus before VVS in 35 women presenting with both problems. Vaginismus was initially treated using self-inserted dilators and concomitant psychological counseling. VVS was then treated only if dyspareunia symptoms persisted after the vaginismus was successfully treated. The VVS treatment protocol included: avoiding irritants; a low-oxalate diet; application of Ovestin ointment; and biofeedback. Of the 13 women who followed the treatment protocol, six women could have intercourse without any pain, two had minimal pain, three had minimal pain reduction, and three had persistent severe pain and had to be referred for surgical treatment.

In another prospective study involving a “stepwise” approach to treatment, Ventolini et al. (2009) assessed the effects of several different treatments on 74 women presenting with vulvodynia. Approaches used included antibiotic treatment, dietary modification, tricyclic antidepressants, Gabapentin, pelvic floor physical therapy, and psychological counseling. Participants were assessed after each step and another treatment added, if needed. With this regimen, a total of 56 patients improved and achieved “satisfactory” sexual intercourse.

Spoelstra et al. (2011) retrospectively evaluated an individualized, multifaceted, and multidisciplinary treatment program for 70 women with PVD. The program consisted of information about PVD, an educative “gynecosexological examination,” prescription of an inert cream to protect the vestibular area, EMG biofeedback, homework assignments consisting of self-exploration, the use of dilators, and lubrication, a hygienic protocol (e.g., no vaginal douching), and normalizing, reframing, and encouraging sexual activity without penetration. If needed, psychotherapy in the form of either individual sexological counselling or sexological partner-relation therapy was also offered. In cases of persistent PVD, surgical intervention was performed alongside the multifaceted program. The average duration of treatment was 148 weeks and mean follow up was five years. Post-treatment, 52 (80%) of the

women had resumed sexual intercourse; however, only 5 women reported completely pain-free intercourse. There were significant reductions in reported vulvar pain at follow-up.

Critical review – outcome studies on miscellaneous and combined treatments

The methodological quality of the studies in this category was poor. Most of the studies identified were uncontrolled or used retrospective assessment. Some were initial pilot studies of a new treatment (e.g., Pukall et al., 2007). Nonetheless, because of the high risk of bias inherent in these studies, reported findings should be interpreted with caution.

Discussion

The aim of this systematic review was to investigate what treatments for female sexual pain have been evaluated in clinical studies and their effectiveness. For many women who present to physicians with sexual pain, no cause can be easily established and no specific disorder diagnosed. Thus, the decision to include treatments about all types of sexual pain rather than focus on single sexual pain disorders was made. Our approach is consistent with those of other recent reviews (Flanagan et al., 2014) and with recent changes in the DSM-5 (American Psychiatric Association, 2013) where the categories of Dyspareunia and Vaginismus have been collapsed into one disorder: Genito-Pelvic Pain/Penetration Disorder. A review of the evidence about which treatments are most efficacious for women presenting with sexual pain symptoms should help clinicians decide which treatment to consider.

A large number of treatment approaches exist, which can make it difficult for clinicians to decide on the best approach for patients. Topical and systemic medical treatments have generally been found to lead to reductions in, but not complete relief of, pain. In addition, side effects are quite common and for this reason, some guidelines suggest that topical treatments should be used with caution (Mandal et al., 2010). There are a disproportionate number of studies that have investigated Botox compared with other medical treatments; although some of these have shown promising results, in some cases this treatment fared no better than placebo (Peterson et al., 2009). This demonstrates the importance of the inclusion of a control group which, as will be discussed below, was lacking in the majority of the studies. Overall, different treatments need to be prescribed to different women depending on their tolerability and women's preferences.

Surgical procedures have demonstrated high success rates. Vestibulectomy has been shown to be effective in increasing sexual frequency (Bergeron et al., 1997; Lambert et al., 2012; Traas et al., 2006), improving women's quality of sexual life and psychological well-being (Bohm-Starke & Rylander, 2008), and decreasing pain during sexual intercourse (Goldstein et al., 2006; Traas et al., 2006), although the proportion of women reporting complete relief of symptoms has varied across studies (Kehoe & Luesley, 1996, 1999; Lavy et al., 2005; Rettenmaier et al., 2003; Tammola et al., 2011). Such variability in complete relief of pain after surgery suggests less invasive treatments should be considered first by women before undergoing surgery. Indeed, in one long-term follow-up study, response to surgery was comparable to that achieved by conservative management (Tammola et al., 2012). If surgery is preferred, the choice of surgery should depend on the individual patient's problem (e.g., laparoscopic surgeries will be better suited to women with endometriosis or paracolic adhesions) and counselling and support should be provided both pre- and post-surgery (Mandal et al., 2010).

Non-medical treatments have also been demonstrated as effective in a number of studies. Physical therapies, including the use of dilators, electrical stimulation, EMG biofeedback, and physical therapy, as well as programs that encompass a combination of physical therapies, have shown promising results in some studies. The same is true for some psychological therapies, in particular CBT. This supports a biopsychosocial approach to the treatment of sexual problems, as benefits can be achieved from a number of treatment modalities to relieve pain and improve sexual function and psychological adjustment (Bergeron et al., 2001; Bergeron et al., 2008; Danielsson et al., 2006). Unlike most of the medical and surgical studies, a larger number of psychological and physical therapy studies have investigated psychological well-being and sexual satisfaction, which have improved as a consequence of treatment (Goldfinger et al., 2009; Kabakçi & Batur, 2003; Ter Kuile & Weijnen, 2006). Although small in number, studies involving other treatments such as acupuncture (Curran et al., 2010; Danielsson et al., 2001) and educational seminars (Brotto et al., 2010) have suggested promising results related to improved sexual function and well-being.

An approach to treating different sexual pain problems may be to follow a stepwise individualised treatment protocol, which has the advantage of including a number of treatment modalities and helps eliminate possible aetiologies of the problem (Baggish, 2012; Har-Toov et al., 2001; Pagano, 1999; Ventolini et al., 2009). The integration of different treatment modalities is further supported by studies that have shown combined treatments to

be effective (Bergeron et al., 2016). For example, integrating pelvic floor rehabilitation and CBT has been recommended, although there has been only one controlled trial on integrating these two treatments (Bergeron, Morin, & Lord, 2010). Multidisciplinary involvement has also been suggested in the EAU and other guidelines (Engeler et al., 2016; Mandal et al., 2010).

Methodological shortcomings of previous research

A number of common limitations across the studies reviewed are evident. First, many studies lacked a control group and the high placebo response demonstrated, as well as the observation that women with provoked vulvodynia tend to experience reductions in pain irrespective of whether they receive treatment or not (Davis, Bergeron, Binik, & Lambert, 2013), underlines the need to have control groups in treatment outcome studies. Second, there is a need to ensure that clinically relevant outcomes, comparable across studies, are measured. Third, the lack of long-term follow-up in the majority of studies is concerning; for example, more than half of the studies investigating either medical or psychological treatments did not include any long-term follow-up. Fourth, in most studies the clinical significance of the reported findings was not established. The IMMPACT recommendations for core outcome measures for chronic pain clinical trials provide a reference point for researchers to use for what constitutes clinically significant pain reduction, anxiety reduction, etc. (Dworkin et al., 2005).

Future research and clinical directions

Although most of the interventions described have been reported as effective, many women still experience pain. Studies that investigate the differences between those women that respond and those that do not respond to specific treatments are needed. Further research on mediators of treatment response should be carried out. Sexual pain problems are likely to involve multiple mechanisms, some with a clear management pathway, while others may not be so straightforward (Engeler et al., 2016). Future studies should also focus on evaluating the clinical utility of the DSM-5 criteria for GPPPD, which focus more on fear of pain and penetration than previous diagnostic criteria (American Psychiatric Association, 2013). Finally, as highlighted by Corsini-Munt et al. (2014), current interventions focus almost exclusively on the woman, despite the accumulating evidence that responses by the male

partner may have an impact on women's pain and pain behaviours. Future research should prioritize the development and evaluation of couple therapy approaches. A move away from the focus on intercourse as a goal of treatment is also needed. In clinical settings, the importance that women and their partners (and sometimes clinicians) place on intercourse needs to be challenged. Couples can be guided and counselled to find mutually pleasurable sexual activities that may or may not include penetration. The development and evaluation of integrated treatment programs pose unique challenges, but these programs may provide the best means to target the multidimensional features of sexual pain disorders (Bergeron et al., 2010).

Chapter 4: Exploring the Experiences of Women with Chronic Pelvic Pain

The findings in Chapter 3 have shown that a number of treatment approaches exist for women with sexual pain. Because sexual pain is commonly experienced by women with CPP, the systematic review in Chapter 3 would be useful in helping clinicians decide on what treatment approach to take. However, the results from the systematic review do not provide information on the first hand experiences of women with CPP. Exploring the first hand experiences of women with CPP is important in understanding how they are impacted by their pain. This in turn could help determine what treatment approaches would be more appropriate. Because of this, a qualitative study exploring the experiences of CPP was conducted and is presented in Chapter 4.

Introduction

As discussed previously in Chapter 1, CPP can have a negative impact on women's lives. Women with CPP have been reported to have poorer physical and mental health scores than normative UK population scores (Zondervan et al., 2001). A large proportion of women have reported to feel lethargic, fatigue, and the inability to carry out activities without taking analgesics or rest (Zondervan et al. 2001). Women with CPP are also more likely to experience sleep problems compared to those with no pelvic pain (Grace & Zondervan, 2006). As well as physical problems, women with CPP experience a significant amount of psychological distress (McGowan et al., 1998). Moreover, they are more likely than pain-free women to experience depression, anxiety, and neuroticism regardless of whether they do or do not have any obvious physical pathology (McGowan et al., 1998).

Previous qualitative studies have further explored the impact of CPP. Such studies have found that women with CPP experience profound pain, dyspareunia, delays in diagnosis, diminished social relationships, negative impact on work, negative effects on emotional well-being, and mixed thoughts about the future (Denny, 2004, 2009; Gilmour et al., 2008; Huntington & Gilmour, 2005; Jones et al., 2004b). Many women have expressed feeling worried that their symptoms would return after treatment and have felt unsure of their ability to cope with the condition in the long-term (Denny, 2004). Other negative

consequences of CPP included feelings of powerlessness and a fear that the women's daughters will also develop the condition (Jones et al., 2004b). Not only does CPP impact the individual women but it is also an emotional and painful experience for couples and symptoms could disrupt everyday life as well as intimacy (Butt & Chesla, 2007). Delays in diagnoses have been frequently reported and possible reasons include the normalisation of symptoms by women and doctors, the suppression of symptoms through hormonal medication, and the use of ineffective tests that result in a high number of false-negative results (Ballard et al., 2006).

Although there have been a number of qualitative studies regarding CPP, more studies of this kind are needed to gain greater insights into CPP with the aim of improving pain, healthcare, and quality of life. Much of the past research has explored women's experiences with healthcare services (Ballard et al., 2006; Butt & Chesla, 2007; Grace, 1995; Price et al., 2006; Savidge, Slade, Stewart, & Li, 1998). Other studies that have explored the impact on relationships and quality of life have focused on particular conditions (Denny, 2004; Denny & Mann, 2007). This study recruited women with a number of diagnoses and all had CPP.

The aim of the study was to gain further insight into women's experiences of CPP in terms of their ability to cope with the pain and their perceptions of how the pain had impacted their ability to work, socialise, engage in hobbies, exercise, and personal relationships. This was achieved by conducting in-depth interviews with women with CPP. The current study differs from previous studies because it included women with a range of different CPP conditions.

Method

Participants and recruitment

Women were eligible to take part if they were at least 18 years of age, and had experienced CPP for a minimum of 3 months. Sampling was purposive and the sample size was determined by data saturation, which is the point in data collection and analysis at which no more themes can be identified and new information produces little or no change to the thematic map (Guest, Bunce, & Johnson, 2006). The study was advertised in seven different local newspapers (Daily Echo; Hampshire Chronicle; Basingstoke Gazette; Andover Advertiser; Romsey Advertiser; Portsmouth News; and Bournemouth Echo) and 5 different

UK charities (Pain UK; Pelvic Pain Support Network; Women's Health Concern; Vulvar Pain Society; and Endometriosis UK). The adverts consisted of a brief explanation of the study including the study aim, confidentiality information, and a contact email (see Appendix G). Women volunteered by emailing to take part and were sent the study information sheet and consent form (see Appendix E). The consent forms were sent back to the researcher before arranging the interview. The women were screened for their eligibility by email and again just before their interviews began. Participants' expenses (up to £20) were reimbursed if agreed in advance and they were given the option of choosing to have the interview either on campus in a private room, on the phone, or in their own homes. A total of 25 women were recruited.

Procedure

Ethical approval was obtained from the University of Southampton's Psychology ethics committee. At the start of each interview, participants were provided with an explanation of the study, were informed that the interviews were going to be audio-recorded and were given the chance to ask any questions. Interviews were in-depth, semi-structured, and followed an interview guide (see Appendix H). The interview guide included topics regarding pelvic pain, work, friendships, hobbies, mood, and personal relationships. Participants were invited to describe their experiences of CPP and freely talk about issues that were important to them. The interview guide was developed by an MSc student who was working on a similar project. The questions on the interview guide aimed to find out as much as possible how the participants had been impacted by their pain in all aspects of the life. Feedback was also obtained from supervisors to ensure the interview guide covered all the relevant topics and that the wording used was clear. Each interview started broad with the researcher asking the participant to say a little bit about themselves. The questions were developed with the aim of trying to cover as much of the participant's life as possible that had been affected by their pain. The questions were revised and developed after receiving feedback from the research supervisors. Each question in the interview guide also had a number of probe questions such as "Please tell me more about this" and "Tell me about how that made you feel" The probe questions were designed to obtain a deeper understanding and reflection of topics discussed by participants. The interviews were shaped by the participants and the interview guide was used more as a reference point to ensure the relevant topics had been covered. This allowed the interviews to flow more naturally and made the discussions

less rigid and more relevant to each participant. In addition, the open-ended nature of the interviews allowed the participants to direct the interviewers to topics and emotions they were comfortable raising. At the end of each interview, participants were thanked for their time and sent a study debrief sheet (see Appendix F) The length of the interviews ranged from 35 to 90 minutes.

Data Analysis

The audiotapes were transcribed verbatim by two researchers (15 by M.A and 10 by P.L²). This was to develop the researcher's interviewing skills throughout the study to ensure rich qualitative data was obtained. Data analysis followed a thematic analysis approach, which involves identifying, analysing, and reporting patterns or themes within the data (Braun & Clarke, 2006). A thematic approach was chosen over other qualitative methods because it is a flexible approach in terms of sample size, theoretical framework, and data collection (Braun & Clarke, 2013). Because the purpose of analysis was not to focus on the perspectives of individual cases or small datasets, IPA was not used. Grounded theory was not used because this method involves constructing a theory from the data. Rather than construct a theory, the aim of the study was to explore common themes among women with CPP conditions. Finally, discourse analysis was not used because this method is based on a theoretical framework that considers emotions and the self as social processes rather than private or individual (Braun & Clarke, 2013).

A theme has been defined by Braun and Clarke (2006) as 'something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set' (p. 10). An inductive approach was used; i.e., analysis was data-driven rather than based on any pre-existing coding frame. Transcriptions were initially read carefully to identify meaningful sections of texts, which were allocated codes. Codes were then grouped together into themes. Some codes could be grouped in more than one theme. A detailed account of groups of themes within the data is provided in the next section.

Results

² P.L was an MSc Health Psychology student who collected the same data for the MSc dissertation

Sample characteristics

Of the 25 women that took part, two were interviewed face-to-face and 23 were interviewed on the phone. Fifteen were conducted by the primary thesis researcher and ten by a MSc student who was working on a similar project. Participants' demographic information is presented in Table 4 (Appendix I).

The majority of the women were in a relationship. The most common condition experienced by the women was endometriosis followed by vulvodynia, although it was very common for the women to have experienced more than one condition. The women overall experienced their pain over a long time with an average length of 8.5 years and only received a diagnosis an average of 4.3 years ago. Throughout the results section, extracts from the interviews will be used to illustrate and clarify the findings. "PPT" is used to indicate the participant, which will be followed by the participant number, the diagnosis, and the page and line number of the extract. The use of "I" indicates the interviewer. The use of "P" indicates the participant when the extract consists of a dialogue. Methods used by the women to cope with the pain will first be presented, which will be followed by the main study themes.

Methods used to cope with the pain

Many women described ways they coped with their pain. Because these descriptions did not focus on the impact of CPP, they are not included as a "Main Theme". However, the descriptions provided a useful insight into the different coping strategies used by the women. These included the use of over-the-counter painkillers, including paracetamol and ibuprofen, and heat methods such as hot water bottles, heat pads, hot baths, and electric heat blankets. Prescribed medications or treatments that were used included codeine, amitriptyline, nortriptyline, gabapentin, tramadol, lidocaine, antibiotics, steroid creams, pudendal nerve blocks, hormone replacement therapy, mirena coil, duloxetine, fluoxetine, oramorph, pregablin, and the contraceptive pill. Non-medical treatments received included CBT, physical therapy, TENS, acupuncture, relaxation techniques, psychosexual counselling, mindfulness, pain management, physiotherapy, and biofeedback. Surgical treatments included vestibulectomy, laparoscopy, laparotomy, and hysterectomy.

Some women used other methods to cope with their pelvic pain, which mainly included engaging in activities to distract themselves from the pain, these did not necessarily stop the pain but sometimes helped improve mood:

“...I try different things, I try umm.....I try err umm, I try, I, I cross stitch, so I try and do things like that to.....to like distract me from my pain...(PPT15; symphysis pubic dysfunction; p8; l275)

Alcohol consumption to numb the pain was also reported:

“.....I started drinking it sort of eased the pain, like I used drink as a pain killer....” (PPT9; endometriosis; p1, l3)

“um I suppose the only thing is that the one treatment I have found that will numb the pain every time is alcohol which is a, a bit worrying. And....loads of women said the same thing, that alcohol is the guaranteed, like you can take the amitriptyline, it won't touch it, then take lidocaine, won't touch it, they can have a bottle of wine or several vodkas and feel like a new person..... (PPT20; vulval vestibulitis/ irritable bowel syndrome; p17, l598)

The second extract highlights how not only does alcohol numb the pain, but the participant also felt like a “new person”. This might suggest that the pain experienced is perceived to be part of her identity. Another concerning finding is that the extract suggests the consumption of alcohol to cope with the pain is common in women with CPP, which can potentially lead to substance misuse.

Main Themes

A thematic map is presented in Figure 2 (Appendix J). Eleven main themes were identified:

- *Problems with general functioning* (subthemes: “Everyday activities are difficult with the pain,” “Feeling fatigued and problems sleeping,” “Difficulties with planning,” “Pain has stopped sports, exercise, and hobbies,” “Social impact of pain”)
- *Medical experiences* (subthemes: “Problems with the healthcare system,” “Negative interactions with healthcare professionals,” and “Importance of a diagnosis”)

- *Can't talk about pain* (subthemes: “The pain is personal” and “People don't understand and can get fed up”)
- *Work and education* (subthemes: “Negative impact of pain at work” and “Work helps with pain”)
- *Cognitive and emotional consequences of the pain* (subthemes: “Suicidal thoughts,” “Emotional wellbeing,” “Pain changed who I am,” and “Concern with having children”)
- *Pain and the relationship* (subthemes: “Negative effects of pain on the partner,” “The pain tests the relationship”, and “Positive relationship outcomes”)
- *Pain and sex* (subthemes: “Sex hurts,” “Sex: “A dimension that is lost in the relationship,” “Role as a “normal wife/woman” and “What sex means to me now...”)
- *The pain is vague* (Subthemes: “The pain is “normal”,” and “Can't “see” the pain”)
- *Positive outcomes of the pain*
- *Financial implications* (subthemes: “Medical costs,” and “Financial implications of not working”)
- *“Other people have it worse...”*

Problems with general functioning

This theme, which reflects the way in which the women’s CPP had impacted their day-to-day functioning, was grouped into the following five sub-themes: ‘Everyday activities are difficult with the pain’, ‘Feeling fatigued and problems sleeping’, ‘Difficulties with planning’, ‘Pain has stopped sports, exercise, and hobbies’, and ‘Social impact of pain’.

Everyday activities are difficult with the pain (contributed by 14 participants)

The women talked about how a number of everyday tasks were negatively impacted because of the pain. Such activities included housework, picking things off the floor, talking, driving, and going up the stairs. This is illustrated by the following extract:

P: Err.....it's, it's just affected everything, I can't.....I can barely cook, you know even just peeling the potatoes hurts my back as silly as it sounds, picking up an empty carrier

bag off the floor hurts my back, you know it's got to that point where any slight movement of anything makes my back hurt, and that's the lower back and the upper back now. errrrm, you know, that's, I can't help my mum with the, you know, the housework, the hoovering, the mopping, even the sweeping it's you know, anything of that sort I can't do. I'll be out for the rest of the day and probably the next day, if I was to do that.

I: Hmmm.

P: Hmmmmm what else is it.....just everything, everything, you know, I'm trying to think if I've missed anything out. It is just, you know everything in life you can possibly think about, it's affected. (PPT6; endometriosis; p14; l532)

The impact of doing an activity or going out somewhere was talked about quite frequently. Many participants anticipated the need to have the day after the activity or even a whole weekend free to recover. This is highlighted by the following extract:

.....if I do something, ummmm, I will then have to block out the next day because I'm going to be....too tired, and to be able to do anything else, so it's quite consuming, it's not just like I could go out for an evening or go shopping for a day, it would sort of then make me too exhausted for the rest of the weekend to do anything else, so, yeah, it's not easy (PPT5; endometriosis; p5; l55)

This suggests that activities and outings had to be planned, ensuring there was adequate time to rest afterwards. This would be difficult and was not always practical, which could deter the women from engaging in different activities.

Problems with sitting were by far the most common everyday complaint. For some women, not being able to sit for long periods of time rather than the actual pain itself, was what directly impacted activities, for instance:

P: Erm, I don't make appointments, I don't go out I don't see friends 'cause I just don't know how I'm gonna be. I've not, we've not had a holiday for two years because I couldn't sit on an aeroplane, I couldn't, I can't travel in a car any more than about 20 minutes, I'm uncomfortable, I have to move, I have to get up, I have to walk around. I don't sit, most days I don't sit all day long.

I: How does, how does that make you feel when you know...

P: Err, well terribly depressed (PPT19; no diagnosis; p5; l142)

Other participants highlighted how being able to sit is something that should not be taken for granted and it is a big part of life. Experiencing pain when sitting could affect the participants' life immensely; this is captured in the following extract:

.....sitting somewhere, you know the simple, you don't realise until you have pain when you sit, how much of your life you do sit actually it's unbelievable. Um, it's something you take for granted um when you can do it, it's just, yes it has affected my life immensely. (PPT21; chronic pelvic pain syndrome/ neuropathic pain; p13; l485)

Some women talked about how difficult it can be to know when to stop doing an activity to prevent the pain from worsening, while also not doing too little activity. For example:

P: So, we're sort of you know, um, so it, it is, I am realising that um, I have what I'd say like a very limited area of things that I can do. There's like a boundary, if I stay within that boundary, it's manageable um it's in the back ground, I can cope but if I step over that boundary of activities the um, I will, will pay for it maybe as I say that evening, or the next day or two days later. Um, which actually makes it quite hard because sometimes it's quite hard to pinpoint what sort of activities can actually, um, are making it worse um, because you don't know um, really (PPT21; chronic pelvic pain syndrome/ neuropathic pain; p12, l433)

The participant discussed how getting the right balance is difficult because it is not always clear which activities worsen the pain and need to be limited.

A number of women discussed how they found it painful to wear certain clothes, mainly trousers, jeans, or underwear that were tight:

Yes, that's when I've got the pain, it's like you can't bear anything to be near that area even the thought of like putting tights on or trousers or like leggings you know tight trousers or jeans or anything, there was just an absolute no no, there was just no way in the world I could even think about putting those things on. (PPT23; endometriosis/neuropathic pain; p17; l575)

For some women, not being able to have the freedom to choose what they want to wear was described as a "battle" that was experienced every day:

...it's rubbish, 'cause you want to be able to you know, wear what you wanna wear, when you want to wear it, you know it's always a battle every morning to be like well what should I wear. You know, I think yeah, it's just more of a battle than anything, every day, trying to be like well what can I wear today that's not going to irritate my skin. (P16; vulvodynia; p10, l335)

Feeling fatigued and problems sleeping (contributed by 8 participants)

Some of the women talked about feeling fatigued or worn out from the pain, which had impacted their ability to function. Some needed to take naps to be able to cope:

....But on a Saturday and Sunday I will lie in and it, I will still go for an afternoon nap because I'm just so knackered half the time to be honest (PPT9; endometriosis; p13; l421).

Because the pain is chronic, it had become something that needed to be coped with daily and had become part of life, for example:

....and I get chronic fatigue as well now because my body has sort of been through so much, umm, it's just exhausting and you feel like you're in a constant battle with err, with everything really, just trying to get through and just carry on life as normal without it, umm debilitating you too much, ummm, and it's all...it, it's always there, it sort of takes over everything and umm.....it....yeah it just, at the moment it's so, I feel quite worn out by it all... (PPT5; endometriosis; p10; l350)

It was frequently mentioned that the pelvic pain experienced could get intense enough to stop the women from being able to sleep or even wake them up at night and preventing them to get back to sleep:

"...I'm not getting any quality sleep 'cause it keeps me up..." (PPT17; vulvodynia; p6; l197)

"....this is my experience, of, of sleep, sleep's been a.....problem too because the pain can be.....at my worst woke me up and I couldn't get back to sleep....." (PPT14; polycystic ovary syndrome/irritable bowel syndrome; p3; l78)

Difficulties with planning (contributed by 9 participants)

The unpredictable nature of the pain was frequently discussed and made it difficult for the women to be able to plan to meet friends, go out with their partner, or go on holidays. This is captured by the following extract:

...we can't make plans, umm because you never know if I'm gonna be ill or not, so you.....don't go on holidays, you don't ummm, plan to go and meet up and have a barbeque with friends, or you don't....you don't, I don't do plans, that's the easiest way to say it (PPT9; endometriosis; p4, l110)

Plans were avoided because the women could not be certain if they would be feeling pain or not. For some, pain was more than likely to occur and so there would be no point in planning anything. Making plans without being able to predict how bad the pain will be tended to lead to cancellations, which most of the women felt bad about and women said they would rather not make plans at all than have to cancel them. For example:

...I don't tend to make many arrangements in advance now ummm, because I don't know, I might end up having to cancel them and I'd rather not make them at all than cancel them, ummm and I would probably say that as a result of that you don't get asked to do many things with people because I think they think we just won't come. (PPT5; endometriosis; p5; l146)

Pain has stopped sports, exercise, and hobbies (contributed by 16 participants)

Because of their pain, many women talked about how they could not do many physical activities, including sports, exercise, and hobbies. Some women even said they had to completely give up a particular sport or hobby that had been a big part of their life:

Well as I say it affected my, 'cause I was quite a keen runner so it, that, that's a big part of my life... (PPT24; vulvodynia; p12; l399).

Because of the pain, some of the women found it hard to do certain movements such as bend or lean forward, which in turn would limit them in what activities they could take part in. For instance:

I: Yeah. Um, OK. Err you, you talked a bit about ballroom Latin dancing...

P: Yes

I: You said you can't do that anymore...

P: No, I physically can't do it. Um, I just can't I mean you know because of the movement involved. I struggle to say go for a walk for 20 minutes, I can't, I can't garden anymore because I can't do the, I can't do the bending or the kneeling down or the leaning forward so. (PPT21; chronic pelvic pain syndrome/neuropathic pain; p15; l533)

Not only did the pain have a physical impact but it could also have cognitive implications that made it difficult to focus on a particular task. The following extract highlights this:

..... if the pain gets too bad I can't concentrate, so umm like the sewing is so intricate, you, you can't do that if you can't concentrate, but I spent most of last night unpicking bits that I'd done, because I knew they were wrong, and they were wrong because I wasn't concentrating, I was in pain.... (PPT7; endometriosis; p13, l491)

The above quote indicates how not being able to concentrate because of the pain negatively impacts being able to engage in hobbies like sewing.

Social impact of pain (contributed by 14 participants)

Although the women's CPP mainly had a negative impact on their social functioning, there were some positive outcomes reported. A minority of the women reported feeling lucky to have supportive friends around them: *...the friends I make are usually through work and, they're generally very sort of...understanding, supportive people, so I suppose I'm quite lucky umm in that way. (PPT11; endometriosis; p12; l428)*. Even though the friends may not have fully understood the pain itself, being able to understand the struggle that comes with it was seen as positive: *...I mean yeah I've got two really good friends who, well she may not understand the pain but she understands.....that I struggle and she understands that I need help with things like that. (PPT15; symphysis pubic dysfunction; p10, l358)*.

The majority of the women talked about how their pain had had a negative impact on their social functioning. The women found it difficult to go out often because of their pain, which meant that they would not be able to engage in social activities others wanted to do and missed out on social events. Friends also tended not to want to come and visit the women at home and seemed uninterested in making an effort with the friendship. This could be difficult to come to terms with, especially when many friendships are lost in this way:

....I had friends in the.... well they're not friends obviously but, ummm, friends in the past that have.....that u haven't been able to then, let's say go the pub or do the social things they want me to do, but then haven't really been.....been bothered to see me, ummm, so, and then you think your friends are people and then they're not really interested in...that can be, quite difficult.... (PPT5; endometriosis; p5; l150).

In addition, the women discussed how when the pain was there, it would make them not want to go out and see or speak to anyone: “....when the pain was there erm, I didn't wanna see anyone, um I didn't wanna talk to anyone so....” (PPT23; endometriosis/neuropathic pain; p11; l376). Because the women experienced their pain frequently, and in some cases constantly, this is likely to have happened repeatedly and have negative consequences on friendships.

Medical experiences

All of the women discussed their medical experiences with the NHS to some extent. These have been divided into the following sub-themes: ‘Problems with the healthcare system,’ ‘Negative interactions with healthcare professionals,’ and ‘Importance of a diagnosis’)

Problems with the healthcare system (contributed by 12 participants)

The majority of the women expressed negative experiences with the national healthcare system. This included delays in obtaining a diagnosis, having to wait through long waiting lists to see a specialist, and the lack of follow-ups and support. The following extract highlights how long it may take to obtain a diagnosis:

Umm it was about 4 months, yeah on and off to go and keep going back.....I went to the doctors probably about umm 6 or 7 times before they told me to go to the GUM clinic where they finally just diagnosed me (PPT10; vulvodynia; p1; l33)

Moreover, the waitlist for seeing a specialist could take six months or possibly more: *Well I'm on their waiting list now which is 6 months, which is, you know, absolutely ridiculous... (PPT6; endometriosis; p2; l60)*

The women also talked about how disappointing it was to not have a follow-up appointment to see how they were coping after being given treatments:*there was no real follow up I don't think at all which is quite disappointing because I thought that coming here, it was gonna get better. (PPT16; vulvodynia; p7; l215).*

Another issue with the medical system raised was the amount of time appointments potentially took, which is significant especially for patients with regular appointments:

....*and hospital appointments will take you half a day because you've got to get there, you might have to wait a long time, so on average every....you know, at least once a month, but every couple of weeks probably I'm half a day in a hospital, which is, again frustrating and annoying and I just you know.....and (unclear) I'd rather not be doing that. (PPT12; vulvodynia/dyspareunia; p14; l542).*

This participant expressed her frustration at the amount of time she had to spend on appointments every couple of weeks. In addition to the pain experienced, this can further hinder general functioning and performance at work. Another interesting finding was that one participant felt that treatment was very much focused around pain and neglected psychological wellbeing factors such as enjoyment and appreciation, for example:

... *at the moment being quite clinical and quite sort of specific because in a way you're trying to pin point whether this is where I'm going to have pain now try something else, no this is OK, and, and, there is, there is nothing about enjoy or appreciation or anything like that in it...*" (PPT22; lichen simplex; p10; l336)

This highlights the importance of understanding what is important to the particular individual during treatment and that psychological factors also play a significant part of the treatment process. A number of women discussed the importance of support especially during the time of diagnosis. It was generally expressed that support was lacking and that it had to be 'fought for' rather than be offered to them:

...*I don't know that I think there's enough support for people who are understanding as...how it can actually affect you and without asking for things yourself I don't think they're very easily offered. And because, because all the things, all the help I got is help that I've umm researched and asked for myself not things that have been offered or given to me, that's probably the biggest things I think (PPT5; endometriosis; p14; l493)*

Negative interactions with healthcare professionals (contributed by 13 participants)

Many of the women discussed negative interactions with health professionals. Some GPs were described as rude and dismissive, for instance:

...the GP that I saw at that time, umm I don't see her now by choice cause I don't, I don't like her very much, I don't like her bedside manner very much... (PPT12; vulvodynia/dyspareunia; p7; l254)

Ummm.....just really frustrated, and I felt like they kept..... to actually kept.....you know, she kept, was trying to fob me off... (PPT10; vulvodynia; p14; l446)

Perceiving the GP in a negative way led the patient to choose not to go back. Some women felt they needed to go back to see the doctor and because nothing 'physically' wrong was found, the doctors gave the impression that they did not believe them and thought the pain was "made up". Some women reported there was a lack of sympathy from some doctors who, instead of trying to find what was wrong, would just tell the women there was nothing more they could do and send them away: *...there's no erm, no sympathy with it, no well let's have a look and see if we can find, get to the bottom of this, it's there's no more we can do, go away. So, you know, you're left with that. (PPT19; no diagnosis; p10; l335)*. A lot of the women expressed how it was a battle to be heard by the medical professional and that getting the right help and treatment was not an easy process. This battle was made harder by the fact that the women were feeling unwell at the same time:

...it was like a battle because you're already feeling really, really ill, and then, and trying, I was trying to battle the medical people to, almost prove something quite wrong with me and they didn't, they weren't really interested, and so it makes you as, I felt quite low and depressed at the time as well, with having to put up with being in a lot of pain... (PPT5; endometriosis; p3; l100)

One participant had someone close to her to attend the consultation with her to "back up" what she was saying to the doctor and to ensure she was heard:

....I used to have to get, get my mum to come to....umm or my, my parents or, someone to always come with me to back up what I was telling people, just so that they would listen ummm, and when you're already battling with pain and not feeling very well it's really

demoralising to have to try and get people to pay attention to what you are saying, It's exhausting... (PPT5; endometriosis; p14; l501)

The use of the word “demoralising” indicates how disheartened or discouraged the participant felt with battling to be heard. A number of the women spoke about the competencies of the doctors and felt that they were not providing treatment or services that were expected of them, for example:

...so it wasn't a question of looking for someone I was gonna go to and they were gonna give me a cure, it was just making sure that um, I, um, I could maybe, there were ways I could improve the quality of my life a little bit... (PPT21; chronic pelvic pain syndrome/neuropathic pain; p7; l237)

... no one's ever.....scanned, they don't know there could be.....all sorts wrong, but they've never ever.....they just assumed its that one thing and that's what it is..... (PPT15; Symphysis pubic dysfunction; p7; l234)

Importance of a diagnosis (contributed by 9 participants)

The majority of the women expressed the importance of having a diagnosis, even though this may not have eliminated their pain. Having a diagnosis for most of the women validated their pain and made it easier to explain it to others:

I:what was it like when you first got your diagnosis?

P: It was a relief to know that there was actually something wrong with me, it was a relief to know it wasn't all in my head that I could actually do something, I can't.....you can do something about it but you can't in a way, you know what I mean, you just gotta live with it but you know why you are living with it now, it's not.....it's not all up in the air anymore, and you actually can tell people “no, I've got this wrong with me, that's why it's like this,” and I can go to work and go “actually I'm off work because of this, and it's a valid reason,(PPT9; endometriosis; p7; l219)

Another benefit to having a diagnosis was the fact that it made people take the women much more seriously than before the diagnosis, for instance:

...when I could label it as vulvodynia, 'cause instead of going I've got a burny itchy fanny and it hurts (laughs) and stops me doing things, people just don't take you seriously, err and

don't really understand the impact of it but when you label it as vulvodynia on the internet they go oh my god, that's really bad. (PPT17; vulvodynia; p10; l366)

In addition, the period before the diagnosis was described as one of the worse times of the condition because of not knowing what was wrong: *...that was I think the worst stage of, of my condition, when I just didn't know what it was PPT3; endometriosis; p9; l313*). The women discussed how distressing it was to not be diagnosed or understand why they were experiencing CPP. Having a diagnosis gave a reason for their pain, which in turn helped them cope better:

...I think it's mentally actually being able to cope with it a lot better as well, so the pain would have been the same as it was a few years ago, because I didn't know what it was and, didn't know how to cope with it, I found it a lot more distressing than I do now. (PPT8; interstitial cystitis/irritable bowel syndrome; p11; l456)

Can't talk about pain

Many women expressed how they found it difficult to discuss their CPP problem with others. There were a number of reasons for this which were broken down into the following two subthemes: 'The pain is personal' and 'People don't understand and can get fed up'.

The pain is personal (contributed by 7 participants)

One of the biggest reasons for not talking about their CPP problem was that it was considered very personal and intimate because of the location of the pain:

...you can't talk about it, I sort of can but not like you know, if you have a condition that affects your knee, you can say oh I've got this terrible problem with my knee and I have to keep stretching it, OK fine, you can't really say oh I've got this terrible problem with my vagina (laughs) it's a bit like oh OK. Um, so I don't. (PPT20; vulvodynia/ irritable bowel syndrome; p10; l337)

The extract highlights how it is considered socially inappropriate to discuss intimate areas such as the vagina, unlike other body parts such as the knee or arm. Not being able to discuss where the pain is makes it harder to talk about the pain at all, which in turn can make

it difficult to cope with. Other women perceived the pain to be private not necessarily because of the location of the pain, but because of the impact it has on personal relationships and talking about the pain would also mean sharing personal information about the partner, for example:

...I think one of the reasons why I find it hard to talk about it is because it's not just about me, the impact, the main impact that it has.....is on my relationship with my partner, so if I talk about it, umm I'm talking, I'm sharing his stuff as well as my stuff, and I think that's the main thing that stops me talking about it actually...but because the main issues are around having sex with my partner or not having sex with my partner, and how it affects our relationship I think that's what's stops me from talking about it to, to people (PPT12; vulvodynia/dyspareunia; p15; l575)

People don't understand and can get fed up (contributed by 8 participants)

Another common reason for not being able to talk about their pain was because most people did not understand CPP problems: *...I think there is a complete lack of understanding about it, apart from a very few people who understand what's going on... PPT16; vulvodynia; p22; l760*). Many women found that it was easier talking to others with the same or similar CPP problems, although others thought the reluctance of women willing to talk about their CPP adds to the lack of understanding: *...people are so reluctant to come forward with the problem that people don't understand it. PPT20; vulval vestibulitis/irritable bowel syndrome; p17; l623*). The women discussed that they thought it was hard for people to understand the pain because it was not something that was “visible” or obvious, for example: *...yeah my family do you know it's difficult they do try and understand and they, they are supportive, but I think it's difficult because they can't see the pain physically in a physical form they can't see it. (PPT6; endometriosis; p8; l283)*

Moreover, the women felt that if they were to always talk about when they were in pain, people around them would get “bored” or “fed up” of hearing about it because the pain was constant in most cases: *“So, they're bored of it so I don't know I don't really talk about it that much.” (PPT17; vulvodynia; p11; l384)*. Because CPP conditions are not openly talked about or understood, a few women expressed worries of being embarrassed or made fun of:

No, no, people can be very cruel regardless of if they're friends or not so I could only imagine some of the jokes that would go on if you know, even though I don't find it funny but I can only imagine so, the fewer people that know about it as far as I'm concerned, the fewer people can laugh about it (PPT23; endometriosis/ neuropathic pain; p14; l459)

Errm.....it's a bit embarrassing, it's really like such an intimate problem, mm.....and.....and a lot of people just don't know what it is, they've never even heard of it (PPT10; vulvodynia; p6; l188)

Because of the difficulties expressed by the women in being able to talk about their pain, some women found it easier to only talk to professionals or anonymously in private groups where they feel safer to do so:

...I'm happy to talk to somebody who's a professional, who kind of understands the condition, and I'm happy to talk to people on Facebook very openly who are.....on that, there's a, these private groups that no one else can see, they're fantastic and they're a really good resource cause people feel kinda safe to share stuff on there... (PPT12; vulvodynia/dyspareunia; p15; l565)

Work and education

The majority of the women expressed how their pain had had some form of impact on their occupational or educational functioning. These have been grouped into the following subthemes: 'Negative impact of pain at work' and 'Work helps with pain.'

Negative impact of pain at work (contributed by 13 participants)

For a lot of the women, their ability to continue to work or study had been negatively impacted because of the experience of pain at work, problems concentrating, and the need to take frequent time off. This in some cases had led their managers to think they were wasting time at work or to some women no longer being in any form of work or education.

Difficulties with concentration were frequently reported, for example:

So I probably did make quite a few mistakes and do a few things wrong and I was quite forgetful and things like that erm, and that kind of makes it worse because I know how

pressured my job is and I know how very unforgiving my bosses are um you know as far as they're concerned you just, they're lovely don't get me wrong but you're there to do a job and if you then start making mistakes which ultimately makes their life difficult, they won't put up with it for long erm, so that's a lot of pressure as well. (PPT23; endometriosis/neuropathic pain; p12; l419)

...my managers are constantly thinking I'm dossing 'cause I'm away from my desk and I'm trying to concentrate on my work and all I can think about is the pain... (PPT20; vulvodynia/irritable bowel syndrome; p9; l330)

Problems with concentration could lead to work being very challenging and this in turn could lead to increases in pressure to perform well at work. It is therefore not surprising that many women took frequent sick days or a lot of time off work. Other participants discussed how their manager tried to get them sacked from their job, for instance:

....so tired from the pain ummmm, and then I had to spend quite a while off work, errr and work actually, the area manager tried to get me sacked for not being in...and then I tried to come back in early but it was too early and I got really unwell and they had to send me back home again, so, it was a bit of a vicious cycle...(PPT3; endometriosis; p14; l518)

Instead of feeling entitled to take time off work if they were feeling particularly unwell, a lot of the women expressed feeling pressure to avoid taking time off and to limit their time away. This is likely because of a lack of understanding about their conditions at work, which led to them being penalized and judged: “*Yeah, but...because it's not really that heard of, and its, they, they haven't classed it as a disability, you get penalised for it.*” (PPT4; endometriosis; p7; l216). In some instances, the psychological impact of being misunderstood at work was greater than the impact of the CPP itself:

P: ...the only time I felt really depressed was, was when I, I was being bullied at work and I was off work and.....getting all these nasty phone calls and letters and things from my boss, umm, I think that was more to do with how they were treating me.....Rather than, rather than the endometriosis, if they had been supportive and understanding I don't think I would have felt, I would have felt like that (PPT11; endometriosis; p14; l504)

Being misunderstood at work resulted in the above participant to feel very depressed and not fully relax during her time off. This in turn, could prolong her time away from work.

This demonstrates how much of an impact people at work can have on the psychological wellbeing of women with CPP. In some cases, contracts had been terminated and women had lost their jobs. For other women, the pain was so bad that they themselves felt they had to completely give up work altogether, which was described as quite a depressing process:

...but as sort of the weeks went on erm, the pain didn't go away and it was disrupting, I could hardly get back to work, because going back to work, the pain was getting worse during the day I couldn't sit down, I couldn't deal with my patients erm, I tried going back to work and I had to give up again erm and actually it was quite depressing... (PPT18; pudental neuralgia; p3; l89)

Work helps with pain (contributed by 1 participant)

For one participant, work was seen as a distraction from the pain. For example:
Umm.....kind of, I think when I was at work, um.....even though the pain was there, there was stuff to take my mind of it, so I sort of quite liked going to work cause I knew I could have something else to focus on, umm, we think that the pain was worse in the evening from when I got home from work but I think that might have something to do with the fact that I was.....if I was at home, if I was sitting in front of the tv, I'd, I'd focus on the pain a lot more than I would at work, so that made it felt like it was worse.....erm but so I don't think it really affected me at work, I think work actually helped me cope with it a bit more (PPT10; vulvodynia; p5; l174)

In this instance, her CPP did not affect her performance at work but instead work helped her cope with the pain better.

Cognitive and emotional consequences of the pain

A large proportion of the women expressed different thoughts and emotions as a consequence of the pain they experienced. These have been grouped into following subthemes: 'Suicidal thoughts', 'Emotional wellbeing', 'Pain changed who I am', and 'Concern with having children'.

Suicidal thoughts (contributed by 7 participants)

For some of the women, the pain would be so severe or constant that they could not imagine continuing to live the rest of their lives like this: *...if someone said to me you're gonna be like this every day for the rest of your life, I don't think I'd wanna live, you know it's that bad I just, I cannot imagine living like this. (PPT20; vulval vestibulitis/irritable bowel syndrome; p14; l519)*. One woman reported that although she would not go out of her way to commit suicide, ending her life seemed like the only way of gaining relief from her pain. It was reported that she would not necessarily mind if she was killed accidentally by other means:

...if I wasI was really, really low and walking down the street, I'd probably.....umm I'd probably not mind if a car hit me and I died because at least that would, you know I would be.....the pain would not be there anymore, ummm but I'd never go out of my way to do anything stupid but.....I didn't appreciate my life too much at the time because it wasn't a good quality of life at all, and there was no relief, umm, it felt like, you just wanna go to sleep forever basically, that was like the only relief, yeah (PPT10; vulvodynia; p9; l284)

This extract highlights the stress associated with hardly having any relief from the pain. In contrast, another participant talked about how at one point she started to look forward to ending her life:

Erm when I was as bad as I actually started to look forward to killing myself, which sounds a bit crazy but I was actually now, I'd had that in my head, that was going to happen, and I was looking forward to it because it would end the pain. And then I think I was driving home from my mums and err it's quite a drive and err I remember just thinking on the motorway, if I just let go of the wheel, it can be over, quite quickly erm, I remember just thinking what I'm gonna do this now, this is, wow I'm gonna do it, and then I almost shocked myself by those thoughts and thought, now I really am in trouble 'cause actually it wasn't just a passing thought, now I'm actually planning it and I was actually about to let go of the wheel so then I sort of, it almost shocked me at how it, my thought process... (PPT23; endometriosis/neuropathic pain; p7; l214)

Emotional wellbeing (contributed by 15 participants)

This subtheme highlights the emotions expressed by the women as a consequence of their pain. All of the women that participated reported feeling low, depressed, or anxious at some point during their experience of CPP. Feeling depressed was frequently reported, which was related to feeling worthless: *Erm, it, well, really, I mean, because, I, I got depressed over it all you just think oh you know, I'm not worth, you don't feel worth anything... (PPT19; no diagnosis; p6; l184)*. The women who described feeling depressed were quite explicit in how they felt; for example:

...you sort of force yourself back to reality and out of this horrific bubble and of depression erm, 'cause that's how I felt, I felt like I was floating, sometimes I was in the supermarket and I was in a bit of a bubble 'cause no one could see me and I could see out but no one could see in (PPT23; endometriosis/neuropathic pain; p7; l202)

The quote illustrates how this women may have felt there was no escaping her depression as well as not being able to reach out to people. For some, feeling depressed came from a lack of answers, not understanding what was wrong, and why they were experiencing their pain. For many participants, life becomes a struggle because of having to cope with the pain at an emotional as well as on a physical level:

Yesterday in particular, I did get down, very down and by the evening, emotionally I was, I was really struggling um, ahh you just feel like oh, everything's a struggle and you just feel like oh well I can't cope and life's you know, life's no fun anymore basically ... (PPT21; chronic pelvic pain syndrome/neuropathic pain; p16; l598)

Another emotion expressed by the women included feelings of anger. Some women reported that they noticed themselves more angry and snappy when they were experiencing their pain. Other women expressed that their anger came out of the fact that because of their CPP, they have not had the same opportunities as everyone else, which suggests that they have been most likely held back by their pain: *Makes me feel angry because I haven't got the same opportunity as everyone else I suppose. PPT9; endometriosis; p14; l469*). As well as anger, feelings of frustration were also expressed, especially at the unpredictability of their CPP; for example:

I: Do you notice a pattern with your symptoms?

P: No, that's what's frustrating, ummm like I said if I get really tired or if I'm down then definitely they're worse, ... umm so, but there's no, there is no pattern and that's what's so

frustrating. I have flare ups and, and it does...there's nothing to explain it sometimes and, and not, that makes it very frustrating, which also makes it worse because it's quite depressing sometimes because you don't know why it's worse, umm and probably most...will never know, umm on and off why (PPT8; interstitial cystitis/irritable bowel syndrome; p10; l414)

Pain changed who I am (contributed by 7 participants)

A few women discussed that they felt that their pain changed their sense of 'self' or who they once were, for example:

...I worry that I'm not quite the same person as I was then and that I'm different and I know, I'm, I'm, I'm probably quite difficult to live with at times, because of the pain but I'm, it affects me sometimes in terms of I can probably be a bit snappy and tetchy and you know everything when the pain levels are high so... (PPT21; chronic pelvic pain syndrome/neuropathic pain; p20; l747)

This extract illustrates how the pain can negatively impact womens' self identity and they may no longer have felt like themselves. Other women talked about how they felt like different people based on the activities they were still able to do; for instance:

... I think the main thing from my point of view, and.... is that I don't feel the same person I was, in ummm....I was....I was incredibly active, very, very healthy and active and I'm not now, it's takes a bit of cajoling out of me (PPT2; endometriosis; p7; l267)

...I mean the fact that I'm having to wear clothes that I don't feel reflect my personality is one thing I'm, it sounds really silly but when you are, you know into rock music, the clothes that you wear almost reflect the music you listen to and other people can kind of go oh I can tell she's a rock chick, used like have red hair and you know, I don't do any of that anymore... (PPT20; vulval vestibulitis/irritable bowel syndrome; p11; l389)

The impact of CPP on some women's identities was reported to have a profound effect on their self-esteem and some women reported hating themselves: *...Yeah, horrific, I have none, at all, erm I hate myself, constantly, it's a constant battle with hating myself (PPT23; endometriosis/neuropathic pain; p9; l300)*. Other women have expressed a sense of worthlessness, for example:

...I'd got really down and it was like well everything's like no I can't do this and um, I just feel a bit, you feel a bit worthless actually, you feel as if you're, you feel as if you've almost lost a bit of your own, what is it? Identity? You don't, you don't, you've lost something as a person somehow because so much of life has been taken away but you just sort of feel well you know, what can I do, what, what, you just feel like you know you're worthless almost really um... (PPT21; chronic pelvic pain syndrome/neuropathic pain; p17; l603)

Because the participant's CPP has had an impact on a number of areas in her life, the participant felt like a lot of her life has been taken away from her.

Concern about being able to have children (contributed by 3 participants)

Some women expressed worries and concerns about whether they would be able to have children. Reasons for the possibility of not being able to have children varied depending on the condition the women had. Women with endometriosis in particular discussed how their condition made it difficult to conceive and the possibility of becoming infertile. This had strong emotional consequences on the women:

Ummm.....I try not to think about it but, it's hard, you know, no...I don't think any woman should ever have to hear the fact that she might not be able to have kids or, it might be difficult or.....it's, it's very, it's very emotional, I have to say, it's very emotional, especially you know, now that the baby (niece) has arrived in the household (PPT6; endometriosis; p11; l396)

Other women talked about how they began to associate their pain with infertility and how they began to perceive their pain as a constant reminder that they may not be able to have children. For a lot of the women, being a mother was important to them and the possibility of not being able to have children had profound effects on their mood and self-worth, for example:

...I feel the pain come in "oh, I'm just going to remind you I'm still here" pain, "I'm just gonna remind you that this is the pain that's potentially making you infertile, this is the pain that causes you blah blah blah blah", Ummmm "and I'm here, don't forget about me!", and then your mood just almost deflates, you just kind of almost deflate sometimes. (PPT2; endometriosis; p9; l339)

...I think that's gonna hit home, if then it gets to a point where, I'm struggling, you know it's gonna go to IVF or whatever it is. One of my fallopian tubes is already damaged, and that was.....that hit home really hard, you know. I know I've still got one, you know, it's working perfectly well but, you know, it just makes you think oh my god. It, it's horrible, it's such a horrible feeling, you feel like, you're incomplete in a way. I know, you know, I'm not, but it just makes you feel like you're less worthy or something, it did when I first found out... (PPT6; endometriosis; p11; l419)

In some cases infertility became a larger issue than the pain itself: “...I think I'd rather be sick and be pregnant than not.” (PPT2; endometriosis; p14; l531). Fertility problems also impacted relationships with friends who themselves were able to have children:

....I feel absolutely wretched to the point of feeling quite disgusted with myself of how.....ummmmm, jealous and.....ummm I can feel towards my friends who have had no trouble conceiving (starts to cry) and who don't really understand....the condition and the pain in that sense. Ummmm, so every time a good friend of mine, “oh, you know, baby number two on the way blah blah blah” in the same space of time as that we've been trying to conceive one. Ummmm, it, you know, just even conceive... (PPT2; endometriosis; p13; l504)

The participant was jealous at the fact that her friends appeared to have no problems with conceiving while she faced the possibility that she may never have children. The impact this has had was not only highlighted by what the participant said, but also by the change in the tone of her voice, which became very tearful.

Pain and the relationship

A large proportion of the women talked about how their CPP impacted current or past personal relationships. This section has been divided into the following subthemes: ‘Negative effects of pain on the partner’, ‘The pain tests the relationship’, and ‘Positive relationship outcomes’.

Negative effects of pain on the partner (contributed by 11 participants)

Not only did the women's pain impact their lives as individuals, but many women spoke about the negative impact it had had on their partners. The participants spoke about how their partners would express feelings of frustration about there not being anything they could do to eliminate the pain: *...but I think I could just tell he was massively frustrated that there was nothing he could do. (PPT17; vulvodynia; p12; l411)*. In one case, the CPP would be so severe that the partner had to give up work to stay home and take care of the children and the house. This led to feelings of resentment, for example:

...it's impacted every part of our life, and his life as well not just mine, who, he had to give up work, to look after the children, so he, he's resentful about that... (PPT15; symphysis pubic dysfunction; p1; l16)

Other participants felt that their partners became quite dismissive over time and were not always sympathetic. It's as though the 'novelty' of the pain has worn off and the partner would only be more sympathetic when the pain was exceptionally bad; for instance:

Um, he recognises when the pain is really bad, but I think it wears thin because it's so common and so often that he's like, "you're always in pain" like a dismissive "well, you know it's everyday so, kinda get used to it and stuff" it's only when it's really bad that, um, that he'll really recognise it and be really understanding (PPT1; endometriosis; p5; l163)

In some instances, the partner had to do most, if not all, of the household tasks. This has been reported to put quite a lot of strain on the relationship and caused arguments. The participants' limited ability to contribute to household jobs not only created arguments and added strain onto the relationship, but also changed the dynamic of the relationship in some cases. One participant reported how her partner described himself as her "carer" before describing himself as her "partner":

....it's changed things between us, in some ways, and even at one point he described himself as being my carer, then, and, then my partner, which is not what you want to hear, from somebody... (PPT15; symphysis pubic dysfunction; p1; l19)

The women expressed how they felt very bad about the impact their CPP had had on their relationships and felt that it was not fair for their partners to also suffer. Being in a relationship added pressure on some women to be "normal" and be able to engage in different activities that were difficult with the pain e.g., going out. For example:

P: It is always that but that I cry at, having erm, that's how it makes me feel that I just wanted my husband to go because it wasn't fair on him, it wasn't fair on me (continues to cry) erm and the pressure of feeling like I needed to be normal, I just, I didn't have the energy to put a smile on my face.....Erm, or to talk or to be normal or to wake up or to do anything, so I felt that wasn't fair on him.....(crying) and that maybe he should go because then I wouldn't feel that pressure and then I could just get on with just well, ending it really 'cause I didn't want to do that to him, if he wasn't there it would have made it easier for me to do that. (PPT23; endometriosis/neuropathic pain; p5; l164)

The participant expressed a lot of emotion and was very tearful, which may reflect the guilt she felt for her partner as well as the pressure she felt to be “normal” despite the pain. Because the pressure was so strong, the participant contemplated ending the relationship, which may have reflected a sense of responsibility for her partner’s wellbeing.

The pain tests the relationship (contributed by 10 participants)

Many women who were in relationships talked about how their CPP tested and in some cases ended their relationships. The pain was described as the “make or break” of some relationships and the women considered themselves very lucky if their partner was supportive. Difficulties explaining the pain and getting their partner to understand was frequently reported. The women tended to be forgiving in the sense that they believed people would only understand the pain if they themselves experienced it. Nonetheless, partners were reported to underestimate the intensity and frequency of the women’s CPP and in some cases not realise the unpredictability and inconsistency of the pain. For a lot of the women, not being able to discuss their pain with their partners added difficulties to the relationship. Some women reported being too anxious or scared to talk to their partners out of fear of receiving an undesirable response; for example:

I: Have you told him about your endometriosis?

P: I did, but I don't, I didn't tell him, I didn't...I was very panicky about telling him, I got quite anxious, umm I sort of blurted a lot of stuff out and I don't even remember what I said at the time.” (PPT3; endometriosis; p10; l367)

...he doesn't talk to me about it at all, so he doesn't know how it makes me feel, or.....what I'm doing to try and deal with it, or you know.....none of that, so it doesn't feel like we're completely in it together (PPT12; vulvodynia/dyspareunia; p15; l593)

The second extract highlights how not being able to openly discuss the pain can add to feeling alone and instead of the problems being shared between the couple, it remains “her” problem that she needs to deal with. One woman even believed that it might be the relationship itself that was causing their pain. This leads them to doubt their relationship and contemplate ending it. For example:

...so it makes it difficult because it kind of makes me wonder is it him (laughs) basically or is it us, you know, is it our relationship that's...kind of was this, the trigger that, that tipped me over the edge into this kind of vulval pain, umm... (PPT12; vulvodynia/dyspareunia; p2; l45)

Positive relationship outcomes (contributed by 9 participants)

Despite the negatives, some women reported that their pain had positive effects on their relationship. Examples of positive outcomes included loving each other more, feeling closer, and that the relationship had become stronger:

Erm, but I yeah, I definitely feel like we love each other a lot more, we're much closer 'cause of it, 'cause we've sort of had to rally together to get through it all... (PPT17 ; vulvodynia; p14; l499)

In some instances it was reported that the pain had made the relationship better. Because the pain had had an impact in a number of areas of both the womens' and their partners' lives, some couples had become more open with each other and much more affectionate, for example:

Umm.....I think it makes it better to be honest, umm which sounds funny obviously (inaudible) we don't have a sexual relationship and that might sound really strange for a husband and a wife, but we do have a really.....we have loads of contact so we always cuddle and hug and hold hands and all that kinda stuff, umm we talk really openly umm you know I think once you've got passed that there's probably nothing.....nothing that really can be more (inaudible) than that, you know there's, there's nothing that we can't discuss or anything, so I think in some ways I've got a much better relationship than some of my friends or peers... (PPT13; vulvodynia; p4; l127)

In addition to feeling closer, the experience of CPP brought out some really good qualities in some partners who were supportive:

Umm.....I think it sort of.....brought out in him really nice qualities, like I didn't know that he could be this nice about some, like about some stuff and umm.....I suppose it has brought us closer a little bit, so that's a positive thing, umm but to be honest, negatively it, you know, apart from the lack of sex, I don't think it has.....because he, he's been so good about it (PPT10; vulvodynia; p5; l167)

Pain and sex

The most frequently reported impact of CPP on the women's relationships was on their experiences of sexual intercourse. Although this is related to the relationship theme, the data related experiences related to pain and sex were rich enough for this to be a separate theme. Pain and sex were broken down into the following subthemes: 'Sex hurts,' 'Sex: "A dimension that is lost in the relationship,"' 'Role as a "normal wife/woman,"' and 'What sex means to me now...'

Sex hurts (contributed by 16 participants)

Pain, either during or sometime after sexual intercourse was very frequently reported. A lot of the women described their pain as burning, stinging sensations as well as a "raw" feeling as though their skin in the vaginal region was going to split. For some women, the pain only occurs after, rather than during, sexual intercourse; for instance:

...it was always, never painful at the time it was always the aftermath sort of thing I was always either have bladder pain or I'd have real burny stingy skin issues um, we, we probably didn't have sex for 3 or 4 months during the peak of what was going on with me so I'd say from January through to April we pretty much gave up 'cause I, it was really bad... (PPT17; vulvodynia; p12; l418)

...I think a lot of the times it would hurt and I would bleed and.....I would hurt for like the rest of the....time, a few hours afterwards. Ummmm, and but every so often, it didn't hurt, and then you're like "oh, maybe I'm ok, maybe it's just doing it wrong or something", and then

ummmm, then.....it would happen again, and it would just be too painful... (PPT3; endometriosis; p9; l309)

The extracts outline how the pain could get quite severe after sexual activity to the point where the women could no longer engage in sexual intercourse for a number of months. Moreover, the pain could be inconsistent for some women and did not always occur during or after sexual intercourse. Interestingly, some women reported that feeling aroused or an orgasm could trigger pain:

...sometimes I find that if I've had an orgasm or something, the pain will come back with a vengeance. Like something's happened that's triggered something. Err, so during it, I think with all honesty, with all the err, adrenaline and you know that sort of stuff, it, it seems to ease off, then afterwards it's worse. (PPT20; vulvodynia/irritable bowel syndrome; p14; l491)

...I even find errr, sort of being turned on hurts, which is really bizarre, not all the time, sometimes I just get like a shooting pain, ummm..... (PPT3; endometriosis; p11; l407)

This could make it difficult for the women to engage in any form of sexual contact, as this may cause them pain. An association of pain with sex was frequently reported by the women and was indeed a deterrent for sexual intercourse. This is highlighted by the following extract:

...there comes a point where actually we haven't had sex in such a long time, I don't miss it, I don't want it, am I bothered not having it-not particularly because there is that one association with it. When the counsellor then suggested well take that out of the equation and just spend time together, that was a lot better for me um, because it's not that I, that I don't want to be with my partner, it's just that if, if one equates sex with penetration, you have no interest because all I can think of is the pain (PPT22; lichen simplex; p10; l325)

Sex: "A dimension that is lost in the relationship" (contributed by 3 participants)

The heading of this subtheme was said by one of the participants and reflects how sex as a whole became missing from the relationship. It was frequently reported by most of the women that they no longer had any desire to engage in sexual intercourse, nor did they find it enjoyable. This was not surprising as most of them found their sexual experiences very

painful. For some women, this had led them to not feel particularly “sexy”, which put them off wanting to have sexual intercourse; for example:

...my libido has.....really taking quite a severe beating to the point where I don't feel particularly sexy, I don't really feel because of the pain, that can incur during intercourse. Don't actually necessarily want to go through that pain. Ummm, so then of course, I'm sort of trying to find ways of wriggling out of things, or not starting something I'm not prepared to finish (PPT2; endometriosis; p8; l289)

I mean I got no sexual feeling, I don't feel sexy, and don't think you know I need sex or whatever, I just don't, don't whatsit, don't, no feeling whatsoever to be quite honest. (PPT19; no diagnosis; p7; l224)

Both participants reported that because of their pain, any desire to have sexual intercourse was significantly reduced to the point where they no longer felt they wanted to have intercourse. One participant reported that she did not remember the last time she had engaged in enjoyable sex:

...I can't think of the last time I had a pleasurable sexual encounter involving in both myself and my partner, you know, ummm but...that we both enjoyed at the same time, penetrative sex wise, I can't remember the last time we had that. (PPT7; endometriosis; p9; l335)

Many women no longer engaged in penetrative sex with their partners as a consequence of the pain experienced and low sexual desire and enjoyment. Instead of penetrative sex, some of the women reported in engaging in non-penetrative sexual activities or ‘foreplay’ to avoid the pain experienced during and after penetration. Although this may seem like the next best option, a lot of the women talked about how it made them feel “inadequate”. In other cases, non-penetrative sexual activities never felt satisfying and not being able to engage in penetrative sex would be disappointing as highlighted by the following extract:

...it's not, generally a good experience for us, and, and I'm talking about penetration and I, again I know lots of people would say “you don't need to do that, there's other things you can do” and that is possible but it kind of never, again, it never feels, that never feels enough, it never feels right and it's...so it always feels disappointing, ummm for us you know (PPT12; vulvodynia/dyspareunia; p4; l125)

Some of the women also avoided non-penetrative sexual activities because of the fear that this would lead to actual penetration; for example:

I: Do you engage in any other non-penetrative sexual activities with your partner such as like foreplay, something like that?

P: Yeah we do, we try to but again it's that whole you know, you feel like foreplay is going to lead to sex err so that, I'm always a bit like I don't want to do it in case it leads to sex... (PPT20; vulvodynia/irritable bowel syndrome; p13; l464)

In contrast, some women felt that it was important to engage in some sexual activity such as foreplay to avoid the threat of the partner satisfying his sexual needs elsewhere; for example:

I: Yeah, have you tried any non-penetrative sexual activities or anything like that?

P: We have to a point, in as much as that we've sort of spend a lot of time together just massaging and being naked in each other's company and all those sorts of things to take away the kind of, almost threatening aspect that, to me because I know you have needs and I'm grateful you're not going elsewhere to satisfy them so shouldn't I be in a position to oblige you... (PPT22; lichen simplex; p9; l317)

Role as a "normal wife/woman" (contributed by 4 participants)

Because a lot of the women had stopped engaging in sexual intercourse, some of them felt that they were not fulfilling a role they perceived to be expected of them as women: "...I wanted my husband to leave because I, I just thought he could probably get another wife who could be a normal wife..." (PPT23; endometriosis/neuropathic pain; p5; l156). A "normal" wife was perceived by the participants as one who could engage in sexual intercourse with her partner, for example:

P: ...So, went to the counsellor and I was kind of treated for vaginismus which did help, it did ease some of the penetration pain but not enough and me and my partner actually split up for a couple of months 'cause it became too much.

I: Yeah, how did, that, how did that make you feel?

P: Um, it was horrible really because I felt like I couldn't be a real woman, I couldn't you know, be what he needed me to be (PPT20; vulvodynia/irritable bowel syndrome; p3; l95)

...I probably would like to speak to a counsellor about what we've been through 'cause I think there's a lot of anger pent up um, and a lot of erm, self-esteem issues I would say, for me, 'cause I felt I felt like when it was really bad, we weren't having any sex so I just felt like well, you know, my role as a wife erm wasn't being fulfilled... (PPT17; vulvodynia; p11; l387)

The second extract illustrates the impact of not fulfilling a role “wife” on self-esteem and anger. Some women became reluctant to start new relationships because of the possible complications involved with having to explain their condition and its consequences.

What sex means to me now (contributed by 7 participants)

As a consequence of the issues the women discussed as described in the previous subsections, the meaning of sexual intercourse had changed for a lot of the participants. For some, it had become about trying to conceive rather than to fulfil a sexual need, for example:

...trying to conceive, in certain times of the month I'm going “come we've got to, we've got to, we've got to!” and after I'll be in pain crying during intercourse cause....it just hurts (PPT2; endometriosis; p8; l295)

Because the desire to conceive was so strong, the above participant forced herself to override her pain and have sexual intercourse with her partner, even though she would have a negative reaction afterwards. For a large proportion of other women, sexual intercourse had become about pleasing their partner and making sure their sexual needs were met. This is also consistent with the “role” some of the women perceived they had, for instance:

...that is exactly how it becomes, it becomes a task that you have to complete in order to try and fulfil what you want and what they want and that it has nothing to do with him at all. Like, it's to do with, I think it's to do with how you see a relationship, how you see the role of the male and the female, you know it's, I think in that respect it has and I can use that word because it really well describes it for me actually, it's a task and as soon as she said it I thought that's exactly how it is for me. (PPT16; vulvodynia; p17; p576)

Other women discussed how they would engage in sexual intercourse for their partner to ensure that their partner's sexual needs were fulfilled:

Erm, well you feel a bit used sometimes but you know at the, he, he's a man, he needs sex, I mean I should be thinking I need it, but I don't so, it's my problem not his. (PPT19; no diagnosis; p8; l235)

This extract reflects that this woman sometimes felt “used” by her partner because she was engaging in sexual activity to ensure his needs are met. She also felt that she should be needing sex and perceived her low sexual desire to be an individual problem with herself rather than a shared problem. Other participants would engage in sexual intercourse to avoid a negative reaction or because they feared that their partner would leave them:

...I ended up getting too scared to tell him if it hurt because he'd get, he'd get annoyed ummmm, yeah so sometimes I would just go along with it for his sake because I didn't want him to leave me. (PPT3; endometriosis; p9; l319)

This extract highlights the difficulties associated with being able to communicate the pain to the partner. In addition, there was the added threat that her partner might leave her if she was not satisfying his needs.

For some women, sexual intercourse equated to feeling close or intimate with their partners. Not being able to have sexual intercourse meant that intimacy was lacking in their relationship. The desire to feel intimate with their partner was expressed more as the participants' need, for example:

... And, because at the same time, you might have the pain but you also have the closeness and everything else with it (participant becomes upset) (pause) it's not necessarily just about me wanting him to feel a certain way, it's about me wanting to feel a certain way as well. (PPT16; vulvodynia; p19; l638)

The pain is vague

Many of the women expressed that they felt that their pain was not clear, especially before their diagnosis, because their symptoms were unexplained. This led some of the participants and/or the people around them to believe that the pain was psychological. Others were told that their pelvic pain was considered “normal” by the people around them and,

therefore, had not become alerted to go and seek help and treatment for their pain. This theme has been divided into the following subthemes: ‘Can’t “see” the pain’ and ‘The pain is “normal”’.

Can’t “see” the pain (contributed by 10 participants)

The women discussed the difficulties that came with not being able to physically “see” the pain. Because the women’s CPP was not obvious on the outside, getting help from medical professionals was very difficult for a number of the participants. In some cases the participant felt that their doctor was getting fed up with them; for instance:

...they actually had no idea what it was, and I kept going back and they just said “oh there’s nothing there, there no like skin complaint or anything” umm and they sort of gave up after a while, I knew that the doctor was getting a bit fed up of me coming back all the time... (PPT10; vulvodynia; p1; l23)

Doctors tended to rely on diagnostic tests to provide objective evidence of a physical pathology. The participants reported how it was a struggle to obtain help in cases where the tests came back ‘negative’. In such cases health professionals tended to believe there was nothing physically wrong with the participants and that the pain was “all in their head.” This could have a negative emotional impact on the women who then did not know where else to turn for help. This is highlighted by the following extracts:

...eventually I went private um, to BUPA where I had two operations erm, to try and find out what it was and they couldn’t find out and they said that I didn’t have anything wrong with me, it was in my head... (PPT23; endometriosis/neuropathic pain; p1; l30)

... I was not in a very good way and I especially wasn’t in a very good way when they were saying that to me and I remember erm thinking I honest- I don’t know what else to do I’m in complete despair, the doctors don’t believe me, what do I have to do, do I have to go to America, you know I don’t know, if doctors don’t believe you or aren’t helping you where do you turn apart from suicide or you know just keep going in a life of misery erm and pain every single day (PPT23; endometriosis/neuropathic pain; p2; l51)

Not receiving a medical explanation or a diagnosis for their pain was reported to give the impression that the women were making their pain up. Moreover, some women doubted

themselves and started to think that it might actually be their mind playing tricks, for instance:

...I think you need somebody in this situation who's there with you because actually you think you might be going mad because you get the feeling people think, some people may think that you're actually making it up. (PPT18; pudental neuralgia; p5; l154)

In addition, the participants expressed that they felt they were not being taken seriously and people would tend to underestimate their pain because they looked healthy on the “outside.” Some participants discussed how people were more likely to take physical injuries seriously because they could see the damage and would not need to be told or reminded what was wrong:

... you need to be taken seriously, that's the thing, everyone, well not that they think it's funny, they just think it's not, you know if you're leg's cut off, or you got a big scar or your hand in a bandage or whatever, people can see that you, you're not well but when you've got pain down there, you've got to tell people that that's what's wrong with you, do you know what I mean and no one really takes it that seriously but err, never mind. (PPT19; no diagnosis; p12; l400)

...on the outside I look completely healthy. And you know.....and inside I'm not what it would appear, so, that's what's really difficult cause nobody can see what's wrong with you. They just, they don't think it could be that bad (PPT2; endometriosis; p15; l559)

The pain is “normal” (contributed by 4 participants)

Some women reported that they first experienced their symptoms during adolescence. Many of them were told that the pelvic pain they were experiencing was “normal” and so they would not have been alerted to get a medical check-up. In some instances the pain would be intermittent and so some women did not think anything of it. The participants that did instigate a medical check-up were also told that their pains were normal “growing pains.” For example:

I: Umm, did you go to the doctors for it?

P: Ummm, I did....I did go at one point mainly because of the passing out ummmm, but they did sort of some general checks and didn't think it was anything, ummm, then I went another time about painful periods and they just said that its normal, ummm for someone of our age to experience that and...I just didn't think to go more into it (PPT3; endometriosis; p2; l57)

Particularly for the women with endometriosis, the pain tended to get worse just before or during their periods. For some of the women that experienced their pain from a young age, the pain would become so severe that they would have to take a lot of time off school. Being told that the pelvic pains were normal for that age led some participants to believe their pain was not as severe as they might have thought so they should just deal with their pain:

At 14, I used to have a lot of time off school, umm because of my age the doctors were saying that ummm growing pain and getting, you know coming to terms with starting periods, that's what they sort of put it down to, thought, oh I just thought that everybody had the same pain, or you know that I was maybe, I was just thinking it was worse and just to shut up and get on with it (PPT4; endometriosis; p1; l8)

Positive outcomes of the pain (contributed by 5 participants)

Although the women mostly discussed how their CPP had a negative impact on different aspects of their life, some reported some positive outcomes. Some women talked about becoming more tolerant and emotionally stronger because of their CPP. The chronicity of their pain had led some of the women to learn to adapt to the physical and emotional difficulties associated with it. In addition, some reported gaining a higher pain threshold. These positive outcomes are highlighted by the following extracts:

...you learn to deal with it, not the pain but you learn to....I suppose....get emotionally stronger if that makes sense. It, it, you know I still get days where....I just wanna cry cause I feel so low, but then you know, you shake yourself off and think "you not, this can't last forever, you know I'm on a waiting list, hopefully, you know, it will all go away (PPT6; endometriosis; p10; l361)

...the pain has always been there but I think, I feel the pain cause my pain threshold has got, I think my pain threshold has got higher... (PPT9; endometriosis; p10; l326)

Another positive outcome expressed by the participants was that the pain had made them more willing to support current research and to read up on the latest treatment regarding their CPP. One participants talked about how they had become part of a charity and have their own blog where they gave advice and support to others with similar conditions. The participant described such activities as emotionally rewarding experiences, for instance:

Yeah ummm, well I recently got involved with the charity, ummm, which I'm really happy about, so now I'm helping hopefully, we're running a support group, so I'm really pleased cause I can now, give advice and support others who are going through the same thing. Ummmm, I also, I run a blog based on it and people kinda write questions to me and I can give advice... (PPT3; endometriosis; p15; l556)

As well as becoming supportive of others, a number of women also expressed becoming more compassionate and understanding of others that also experience a chronic medical condition. Experiencing their chronic pain has given some of the women a different “outlook” and has made them more empathetic of others with a chronic pain condition. The women expressed that they now understand how it is not always easy to come out and socialise and “get on with” their chronic pain; for example:

... it (the CPP) has I guess changed relationships, it's changed the way I am able to erm relate to people who are going through say, difficult times, who have got chronic pain of a different sort erm, I am actually able to empathise with them and I think it's given me a different, completely different outlook. Erm you know when I've, I've seen people with problems, I've got, it's made me a lot more I think, compassionate and understanding (PPT18; pudental neuralgia; p12; l439)

...I suppose until you actually suffer something, you don't understand, I used to get really annoyed with people who had health conditions and had it all their lives, I used to think for gods sakes you know just get on with it and come out and have a drink, you'll forget all about it and now I feel terrible 'cause I completely understand why they didn't want to come out. (PPT20; vulvodinia/irritable bowel syndrome; p11; l383)

Finally, a number of women talked about how their family had become more open with each other as a consequence of their CPP, more specifically regarding their general health. Physical health problems that may have previously been considered delicate issues that are kept private had become much easier to talk about within the family. This is especially true with the women's CPP that may have been considered a female problem and not something that is discussed with male members of the family. In a sense, some families had become desensitized to discussing physical issues, which would not have been talked about in the past.

Yeah I don't say we.....yeah we definitely, we talk about, we talk about our health much more, I think definitely through illness and you know being around family when, when they're ill, you talk to them much more about it and they talk to you much more about it, and I suppose talking about your kind of pain and your....physical problems and your bodily functioning generally becomes much more normal....and I'm quite happy to tell them because I know if I don't tell them they'll worry so, umm I think, I think we're probably much more open to talking about this kind of stuff (PPT12; endometriosis, p13; l476)

Financial implications

All the women talked to some degree about experiencing frequent medical visits, time off work, recovery time, medications, or being unable to work at all. For some women, this had had negative financial implications. These have been divided into two themes: 'Medical costs', and 'Financial implications of not working.'

Medical costs (contributed by 4 participants)

Most of the women would have had to pay for their medications, which would need to be purchased on a regular basis. Some women talked about how the cost of medications had had a negative financial impact. This was especially difficult if the women also had to pay for other expenses and were not in full-time employment:

P: ...the cost. The cost of having to have repeat prescriptions of tramadol and codeine, like today for example to pick the tramadol and codeine up on my way home was £5 for my prescription, and then on top of that the neurofen I take is £10 for a pack, errm, then that's every month.....I have to pay, yeah I have to pay for it. So if you...I haven't got a calculator

on me or is in any capacity to try and add up now, but like, you know, I just think £25 roughly a month....Yeah, it is a lot, and that comes out of my own pocket, with...when I have a mortgage to pay and I'm a full-time student and can't work full-time (PPT1: endometriosis; p9; l275)

Other women had spent a lot on different alternative treatments and specialists with no progress. For some women, payments eventually had to come out of their savings because the costs of the treatments were so high. For instance, the following participant talked about spending money from her savings to support her treatments. In addition, she is not able to work as she was on maternity leave and even though she had already spent a lot on treatment, she was still not better and would likely spend more:

P: ...so, just generally, massively upset with the fact that this has been going on now 6/7 months and I'm still looking for a diagnosis and um, treatment and I've spent hundreds on seeing an acupuncturist and seeing a chiropractor and now I will continue to spend more seeing this physio therapist....Oh yeah, yeah and also, I'm on maternity leave, so we haven't got any, much money so basically spent my savings on medical treatment which was our back up fund in case the boiler goes you know, stuff like that so we haven't got any financial security now.....Which is scary as well 'cause it's all, and obviously we had the discussion about that my husband's like just do it, pay, just throw some money at it and get better but obviously I'm spending more and more money and trying different avenues and I'm still not you know, a hundred per cent better. (PPT17; vulvodynia; p17; l593)

As discussed previously, a number of women discussed how they could no longer wear certain clothes. For some participants this meant having to go and purchase new clothes that were comfortable and did not aggravate their pain. The cost of having to buy a new wardrobe was in addition to the costs of treatment and medical care, which could cause a huge financial strain, for example:

...That's a massive financial outlay just to get some clothes that I can wear comfortably erm you know that cost me hundreds of pounds 'cause you have to buy shoes and all sorts 'cause I didn't have anything, I didn't wear dresses or skirts and obviously there's the financial outlay of the private medical care and the treatment I had to have, that was a nightmare. (PPT20; vulvodynia/irritable bowel syndrome; p8; l278)

Financial implications of not working (contributed by 4 participants)

Some women talked about how they were no longer able to work because of their CPP, which means they do not bring money into the household and would most likely have to rely on their partner financially. This was reported to cause some tension within the relationship and added pressure on the partner to support them both. In some instances this had led the partner to be less sympathetic towards the participant, for example:

P:and that causes a stress on me and my partner's relationship because I don't bring in money to our relationship and house, he's financially supporting the both of us, so he's under a lot of stress. Errm yeah, and then, you know, he says "I appreciate that you are in pain a lot of the time, but you need to do a few shifts, we need the money", so sometimes the sympathy stuff doesn't.....

I: And how does that make you feel?

P: Yeah, sometimes pretty shit because I think he thinks I'm playing on it and I don't wanna do a shift, and its not that way at all (PPT1; endometriosis; p9; l298)

Some women expressed that there was a strain on their relationship because they were spending their partner's money. This is because the participant would feel she had to justify what she had bought to her partner, whereas she would not have to answer to anyone if she was spending her own income:

I: Yeah, do you find it's had a strain on you financially as well?

P: Well yeah, I can't work, I don't have any money so, I mean my husband say well you know, take the money, do whatever, your money's my money but that's not the same thing, you know you still have to justify why you've bought this, why have you done that, what have you spent that money on you know whereas if it's your own money you do what you want. You don't have to answer to anyone but, yeah it does strain... (PPT19; no diagnosis; p9; l281)

In one instance, the partner had also had to give up work to care for the participant experiencing CPP. This caused a significant financial strain, making it difficult for the couple to get by and they had to resort to buying items including clothing, second hand, for example:

...my partner being there to help me stand up, cause the pains that bad, things like that, and people have just.....I, err, people have always been jealous of the fact that.....I have got D home with me all the time, and to be fair its not something to be jealous of because it's.....we, we have no money, we're skint, we save to get by and.....you know, my little girl is going to school and er, she's got a new polo shirt but err, her dress and everything, got all her dresses and everything, got it all second hand, and you know she wanted me to get her new ones, it's cause.....we just can't afford it... (PPT15; Symphysis pubic dysfunction; p8; l298)

“Other people have it worse...” (Contributed by 5 participants)

A number of women spontaneously compared themselves with other women with the same condition but who had it worse in terms of pain and severity. In some cases, this downward comparison would have a negative effect on the participant and would make them feel “weak” or not as strong as other women. For example, one participant would chat to other women on online forums and wondered why she was complaining about her pain when others had it worse:

...umm I mean I often feel a bit of a phoney, I'm on the Face...Facebook forum or a couple of them actually with other, women with vulvodynia and I always feel like I'm the one that, haven't really got it that bad and what am I complaining about, you know... (PPT12; vulvodynia/dyspareunia; p3; l113)

Another participant would witness patients as part of her job who may have multiple severe chronic pain problems. The participant expressed feeling inspired by these patients and saw her condition as unimportant:

P: Like there's, there's obviously, things and I see so many symptoms and so many long-term conditions and diseases that I count mine as quite irrelevant sometimes, I think

I: oh really?

P: Yeah, its because of my position, I, I see patients with, like so many comorbidities that I just think god they are inspiring, they live through you know, 5 or 6 health related issues, and I suffer with one... (PPT1; endometriosis; p1; l35)

In contrast, some women benefitted from a downward comparison and expressed feeling lucky that they were not as bad as some people. This provided them with a more positive view of their condition and is more likely to have a positive impact on their ability to cope with their pain:

...I feel very lucky sometimes but, like I said a lot of people have got it a lot worse, ummm so I suppose I just think of that (PPT8; interstitial cystitis/ irritable bowel syndrome; p6; l221)

Yeah, umm as I said, there are people in a far worse situation that suffer far more than I do, which the same condition and umm in some way I do count myself lucky in that sense... (PPT2; endometriosis; p16; l598)

...so there were some people there who were obviously have a lot worse symptoms than I do which was not nice to hear but you kind of think well there's someone else who has the same thing as me but actually mines not as bad as I thought it was. (PPT16; vulvodynia; p3; l86)

Discussion

The women that participated opened up about their personal experiences of CPP in semi-structured interviews. The key findings were that CPP had had an impact on virtually every aspect of their lives; this included their ability to work, socialise, engage in hobbies, and exercise. Previous research has reported similar findings but mainly for women with endometriosis (Gilmour et al., 2008; Jones et al., 2004b). The current findings reflect a wider CPP population. Consistent with previous research, one of the biggest effects of CPP was on the women's sexual functioning (Butt & Chesla, 2007; Denny & Mann, 2007; Donaldson & Meana, 2011). Because many of the women began to associate sexual intercourse with pain, sexual intercourse started to have a different meaning to them. Engaging in sexual intercourse became either about ensuring their partner was satisfied, conceiving, to maintain intimacy in the relationship, or to fulfil the "female role" in the relationship. In some instances, it was not possible to have sexual intercourse because of the pain, which caused tension in the relationship. Elmerstig et al. (2008) found that the women in their study tended to "sacrifice" themselves in an attempt to live up to their image of an ideal woman and would engage in sexual intercourse (despite the pain) for their partner's sake. The women believed if they were not able to engage in intercourse, their partners would become tired of the relationship and leave them for new women without sexual problems. Although similar findings have

been reported, the current sample included women from various age groups and who were heterogeneous in terms of their conditions. Elmerstig et al. (2008) included a younger sample and any underlying diagnoses that may have been related to their sexual pain was not reported.

Many of the women in the current study preferred to not disclose information about their CPP to people they knew, including friends and people from work. Because the location of CPP is around the female reproductive organs and genitalia most women found it difficult to talk about their pain, which also has been previously reported (Gilmour et al., 2008). A novel finding from the current study was that some women would rather not talk about their pain because of the fact that disclosing information about their pain meant that they were also disclosing information about their partner, which would have led to their feelings of embarrassment, shame, or guilt.

Consistent with previous research, the CPP experienced by many of the women in the current research was frequently “normalised” by either the women themselves or by medical professionals (Ballard et al., 2006; Grace & MacBride-Stewart, 2007). The women with endometriosis in particular would experience greater pain either before or during their periods, which was initially considered “normal” by themselves and other people. Normalising the pain in such a way contributes to the frequent delays in diagnoses. Moreover, for many women, their pain was not “visible”. ‘Positive’ medical tests provided some women with a diagnosis and a level of meaning to their pain, which was usually followed by treatment. If no diagnosis were provided, the women would have to continue their search for an explanation and would struggle to receive help, which is consistent with previous research (McGowan et al., 2007). Another finding consistent with previous literature was that it was important for the pain to be “visible” to the people in the women’s lives and not just to medical professionals (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). Unlike a broken leg or a wound, CPP is internal and cannot be seen on the outside, which meant friends, family, or partners would underestimate the severity of the pain and in some cases forget the pain was there.

Another major impact of the women’s CPP was on emotional wellbeing and general day-to-day functioning, which is also consistent with previous research (Jones et al., 2004b; Schneider & Fletcher, 2008). The majority of the women expressed how they were no longer able to do everyday activities such as housework, sit, or wear certain clothes. The great impact of the CPP on the women’s lives led some women to feel that their pain changed their sense of ‘self’ or who they once were. Some women no longer felt like the same person

because they essentially had to adapt to a new life with CPP, which had a strong negative impact on the women's self-esteem. Although previous research has reported on the occupational impact of CPP (Denny, 2004; Jones et al., 2004b), no qualitative studies have discussed personal financial worries as a consequence of the women's CPP. The chronicity of the women's pain meant that they had ongoing medical costs which caused financial strains. The financial strain was exacerbated in situations where the women were not able to work because of their pain, adding pressure on the partner to be the sole provider. This in turn added to the strain the CPP had on their relationships with their partners. The profound impact of the CPP on the women's lives often led to strong negative emotional consequences, including depression and suicidal thoughts. The explicit expressions of suicidal ideation is a new finding of the current study. Much of the previous qualitative research has discussed the emotional impact of CPP in terms of anger, frustration, or depression (Jones et al., 2004b; Schneider & Fletcher, 2008).

Another novel finding was that many women tended to engage in "downward comparison" with others with worse chronic pain conditions. Interestingly, this had either a positive or negative effect on their psychological wellbeing. For some, comparing themselves with people in worse conditions made them feel weak for not being able to cope with their condition. In contrast, it made some women more grateful for what they were able to do and would perceive their condition to not be as bad as they thought.

Another finding related to positive outcomes of the pain. Some of the women expressed feeling emotionally stronger from having had to adapt to the emotional and physical difficulties of their pain. Some had become more empathetic and compassionate towards others with similar conditions and were willing to support charities as well as research. These positive outcomes may reflect 'posttraumatic growth,' an experience of positive change that results from a struggle with highly challenging life crisis (Tedeschi & Calhoun, 2004). Major domains of posttraumatic growth include greater appreciation of life and changed sense of priorities, having warmer and more intimate relationships, increased sense of personal strength, recognising new possibilities for one's life, and spiritual development (Tedeschi & Calhoun, 2004). Research has shown that posttraumatic growth happens in people facing a broad range of traumatic circumstances such as cancer (Cordova, Cunningham, Carlson, & Andrykowski, 2001), rheumatoid arthritis (Tennen, Affleck, Urrows, Higgins, & Mendola, 1992), house fires (Thompson, 1985), and sexual abuse (Frazier, Conlon, & Glaser, 2001). Experiences of CPP can be traumatic, especially at first, and are associated with a number of distressing emotions that are consistent with people

facing trauma (Tedeschi & Calhoun, 2004). Research investigating posttraumatic growth and CPP is lacking. The positive outcomes found in this study among some participants provide support for the possibility of posttraumatic growth in some women with CPP conditions. This has positive implications for the development of interventions for women with CPP, which can focus on personal growth after the “trauma” of CPP.

The study had a number of limitations, which need to be considered. Apart from two women, all the participants were interviewed over the phone. Important non-verbal communication such as hand gestures, body posture, facial expressions, and eye contact would have been lost over the phone. Moreover, the participants who phoned in would have missed nonverbal communication from the research, which would likely have made it easier to build rapport quicker and potentially resulting in richer data. However, it could be argued that given the nature of the research topic, the women may have found it easier to phone anonymously than to travel to be interviewed in person. This also meant that participants were less likely to cancel their interviews. In addition, having the option of phoning in meant that it was possible to recruit a more diverse sample across the country. Another limitation was that limited demographic information was obtained from the participants. Additional demographic information that would have been useful includes ethnicity, race, income, and education level. Such information may have been useful because there may have been potential themes across certain demographic groups. Finally, though women with a range of CPP conditions were included, a large proportion had endometriosis (N = 10; 40%) followed by vulvodynia (N = 8; 32%). It would have been advantageous if more women with different CPP conditions had been recruited e.g., pelvic inflammatory disease, pelvic congestion. Despite these limitations, there were a number of strengths of the current research. The study had a good sample size that was large enough for data saturation. The women within the sample were generally heterogeneous in terms of their CPP diagnoses, age, relationship status, duration of their pain, and the treatments that they had undergone. This is a strength of the study because the sample is more reflective of women with CPP conditions. Moreover, the interviews provided very rich data and the women appeared relaxed and calm throughout. The interview guide that was used eased the participants into the interviews, allowing them to feel comfortable enough to open up.

Allowing women to tell their own story and exploring how and in what areas the pain has impacted their life served as a positive experience for women and should help inform treatment interventions. Future qualitative research should aim to include more women with other CPP conditions, as most research has included women with endometriosis, vulvodynia,

and dysmenorrhea. The problems as a consequence of CPP discussed by the women in the study were multidimensional and included negative effects on their relationships, sexual functioning, social functioning, general functioning, and occupational functioning. It is important that health professionals acknowledge the diverse impact of CPP on women and how it may affect them emotionally and psychologically. Because CPP is multifaceted, treatment should not only be directed at eliminating pain but should also help improve the QOL of women with CPP.

Reflexive comments

This study was the first qualitative study I had ever conducted and have learnt a lot through the experience. After completing the interview with my first participant, I felt a sense of relief and thought it went well. On reflection, that interview was probably my worst one and I was unaware that I used questions and responses that were leading the participant to respond in a certain way. In addition the in interview did not result in rich data and I could have asked the participant to expand her answers much more. In spite of this, my interviewing skills improved significantly with the more interviews I conducted and I was able to obtain rich data.

Before conducting this study, I underestimated how long data analysis can take compared with quantitative studies. I found transcribing very time consuming and not a particularly enjoyable experience. For this reason, I made sure I set a timer to ensure I gave myself enough breaks. On a positive note, transcribing helped me familiarise myself with the data, which helped with later analyses. I was very relieved when I had finished all my transcriptions and enjoyed re-reading them and highlighting important extracts. Because the data was quite rich, I felt overwhelmed with all the information and initially found it challenging to organise all my codes into manageable themes. There was so much I wanted to include in the final report so tried to keep in mind the importance of not going off topic. This meant I could not plan the structure of the Results section until I had finished coding my data, which was not what I was used to.

Chapter 5: The Development of an Online Questionnaire that Assesses the Impact on Quality of Life of Female Chronic Pelvic Pain (CPP): A Think-Aloud Study

The themes from the qualitative study presented in Chapter 4 were used to develop items of a new measure of CPP. The new measure aims to assess the impact of CPP on a number of QOL domains (e.g. occupation, sexual functioning, and everyday functioning). It was important that the domains were selected based on the themes discussed in Chapter 4 to ensure the items were patient focussed and relevant to the experiences of women with CPP. To further ensure the items were relevant, clear, and covered all the domains women with CPP consider important, a think-aloud study was conducted and is presented in Chapter 5.

Introduction

The experience of CPP can be very disabling for the individual. Women with CPP have been reported to experience more sleep problems than those without CPP, and greater interference of their pain on activities and work (Grace & Zondervan, 2006). In addition, women with CPP have reported more sexual problems, including sexual avoidance, and sexual dissatisfaction than women without CPP (ter Kuile et al., 2010b). Gates and Galask (2001) found that, compared with pain-free women, women with vestibulodynia reported significantly higher levels of depression, psychological distress, and sexual depression (defined as feelings of unhappiness or depression regarding one's sex life" (Fisher, Davies, Yarber, & Davies, 2010). Women with vestibulodynia also reported significantly lower sexual satisfaction, sexual behaviour, and sexual self-esteem compared to women without pain. Gates and Galask (2001) concluded that their study highlighted the psychological distress experienced by women with vestibulodynia and the importance of addressing such distress. Other studies have reported that women with CPP conditions experience significantly more psychological distress, low self-esteem, depression, anxiety, and worse sexual functioning compared to women without pain (Desrochers et al., 2008; Masheb et al., 2004; Nunns & Mandal, 1997).

Qualitative studies have provided more detailed accounts of the impact of CPP. Women with CPP have expressed problems with maintaining friendships and socialising (Denny, 2004; Gilmour et al., 2008), difficulties with work (Denny, 2004; Gilmour et al., 2008), and difficulties being able to cope with their condition in the long-term (Denny, 2004). Jones et al. (2004b) explored the impact of endometriosis on the QOL of 24 women with a

laparoscopic diagnosis of the condition. Using thematic analysis, the authors found that the pain had impacted a number of aspects of the women's lives. Issues identified included worry the pain was due to cancer, problems with everyday functioning (e.g., sitting, wearing usual clothes, eating, drinking), not having enough energy or vitality because of the pain, not being able to attend social events, feeling powerless and controlled by the pain, feeling socially isolated, and feeling depressed or short tempered because of the pain. Schneider and Fletcher (2008) explored the impact of IBS and inflammatory bowel disease (IBD) upon university aged women. The women that participated expressed powerful descriptions of how their condition had a negative impact on their emotional health in terms of feeling helpless, embarrassed, and guilty. The emotional impact in turn had a significant effect on their QOL.

A number of studies have explored the impact of CPP on sexual functioning and relationship satisfaction. Most women with CPP experience pain with sexual intercourse which can lead to feelings of inadequacy as a woman and as a partner because of the thought of not being able to satisfy their partners sexually (Ayling & Ussher, 2008; Denny & Mann, 2007; Jones et al., 2004b; Sutherland, 2012). This then results in feelings of shame, guilt, and decreased sexual desire (Ayling & Ussher, 2008; Sutherland, 2012). The lack of sexual relations has been reported to often lead to tensions and arguments within the relationship (Denny & Mann, 2007). Painful intercourse and strains in relationships can be concerning for women and many continue to have intercourse with their partners despite the pain, to ensure the relationship is maintained (Azevedo et al., 2005; Sutherland, 2012). Coping strategies used to deal with sexual discomfort and pain include avoiding sexual intercourse, not being psychologically present during a sexual encounter, or engaging in compensatory behaviours e.g. alcohol, housework, or overeating (Sutherland, 2012). In addition, some women feel exhausted, hurt, and angry over not having their needs met while meeting other's needs (Sutherland, 2012). Butt and Chesla (2007) examined the relational impact of CPP on couples and found profound grief reported by couples with CPP from the loss of the sexual relationship they once had, and the pain-free and active life they once shared, and from dealing with infertility.

Despite the many problems faced by women with CPP, seeking medical help can be problematic. Women have expressed frustration at the lack of knowledge about CPP shown by doctors, delays in diagnosis, and thought that they were wasting doctors' time because they believed that the doctors thought that the pain was in their mind (Ballard et al., 2006; Denny, 2009; Jones et al., 2004b). Those that experience pain in the absence of physical pathology tend to report negative or even stigmatising medical encounters (McGowan et al.,

2007). The experience of consultations where women felt they have not been heard and the discrepancy between the doctor's and a woman's interpretation of the consultation contribute to disengagement with the medical system (McGowan et al., 2007). Moreover, the way women are informed about negative test results can have negative emotional consequences. For example, in a qualitative study by McGowan et al. (2007), a participant expressed her distress, disappointment, and confusion when she was informed no pathology was found at laparoscopy. Women with CPP want to be taken seriously during their consultation as well as given reassurance, personal care, and an explanation for their pain as much as a cure (Price et al., 2006). Before obtaining a diagnosis, women have expressed difficulties in being able to open up about their pain and explain why they are not able to maintain work and home responsibilities (Ballard et al., 2006). A diagnosis provides a medical label and helps validate the women's CPP (Ballard et al., 2006). In instances where treatment has been provided, concerns and worries have been reported in terms of the pain returning after treatment, the experience of side effects, and the treatment not working (Jones et al., 2004b).

A variety of different measures have been used to assess the impact of CPP on women's lives (Jones et al., 2002; Neelakantan et al., 2004). These include a number of non-CPP specific questionnaires that assess QOL [e.g. The Short Form (SF)-36 (Ware, Kosinski, & Keller, 1996)], pain [e.g. The Brief Pain Inventory (BPI) (Cleeland & Ryan, 1994)], and emotional wellbeing [e.g., The Psychological General Wellbeing Index (PGWI) (Chassany, Dimenäs, Dubois, Wu, & Dupuy, 2004)]. Although these questionnaires have been evaluated and demonstrated good validity, they have shown poorer face validity when used with women with CPP (Neelakantan et al., 2004). That is, these questionnaires do not cover all of the topics that women with CPP consider important or relevant to their condition. For example, the SF-36 contains items that assess general health and emotional wellbeing. The BPI strongly focusses on pain levels, pain characteristics, and medication. The PGWI contains items that assess general health and psychological wellbeing. Though these questionnaires are valid, they do not assess how CPP might impact sexual functioning, personal relationships, and occupation. A CPP-specific questionnaire is needed to assess the impact of the condition on more specific elements of well-being and functioning of women.

There are also questionnaires that focus on specific CPP conditions such as endometriosis and IC. These include a Health-Related QOL questionnaire (Colwell et al., 1998), the Endometriosis Health Profile (EHP)-30 (Jones et al., 2001), The ICSIPI (O'Leary et al., 1997), the PUF Patient Symptom Scale (Parsons et al., 2002), and The Chronic Pain Grade questionnaire (Smith et al., 1997). Most CPP questionnaires tend to focus on the

characteristics of pain symptoms (e.g., intensity, duration, pain during sex) with little focus on the impact of the pain. Other disadvantages of these questionnaires include not taking a primarily patient-led approach when designing the questionnaires (Colwell et al., 1998; Parsons et al., 2002); and not taking into account other important areas of life affected by the pain, such as work, relationships, and social life (Parsons et al., 2002; Smith et al., 1997). Moreover, these questionnaires do not adequately evaluate the impact of CPP on personal relationships, which is very important based on the findings from previous qualitative studies (Butt & Chesla, 2007; Smith et al., 2013; Sutherland, 2012).

A questionnaire that can be used to assess the impact of CPP conditions as a whole would have versatile uses. For instance, such a questionnaire would be able to be used by women who have not received a diagnosis for their pain. Additionally, CPP is associated with a number of different conditions, including endometriosis, chronic urinary tract infection, and IBS (Howard, 2003). Treatment usually requires treating the pain itself or global treatment, as well as the possible treatment of specific conditions e.g. endometriosis (Green et al., 2010). A CPP questionnaire that is not specific to a CPP condition would be useful in evaluating treatments that are not specific to a CPP condition. Such treatments can include pharmaceutical treatment, psychotherapeutic, and multidisciplinary interventions.

The EHP-30 (Jones et al., 2001) is one of the very few patient-generated questionnaires in this area. In-depth interviews were initially conducted to explore the impact of endometriosis on the participants' QOL. A pilot study was also conducted to check the face validity of the items generated. The final questionnaire included a number of important domains such as the impact on work, perceptions of the medical profession, infertility, social support, and control and powerlessness. However, this questionnaire was designed specifically for women with endometriosis and therefore may not be suitable for women with CPP who do not have endometriosis.

Quaghebeur and Wyndaele (2013) compared a number of widely used questionnaires for the evaluation of symptoms and QOL in patients with CPP syndrome (CPP). Very different results were found when the questionnaires were compared, making overall conclusions regarding pain and QOL difficult. Although the questionnaires administered all assessed pain, they differed in terms of how pain intensity was measured. This suggests that comparisons between these questionnaires may not be reliable. Quaghebeur and Wyndaele (2013) concluded that the development of a generally accepted questionnaire assessing pain, symptoms, and QOL in patients with CPP is needed to facilitate the interpretation and comparison of studies.

In a systematic review, Jones et al. (2002) reported on the types and psychometric properties of measures that have been used in studies assessing the impact of gynaecological conditions, including CPP. The majority of the studies used generic QOL measures and only five (11%) used disease-specific questionnaires to assess treatment outcomes. These authors argued that the use of generic measures has the limitation of not being sensitive enough to assess changes in health related QOL (HRQOL) across a variety of diseases. Jones et al. (2002) also found that only two of the disease-specific questionnaires were generated from data obtained from participant interviews. It is important to interview the population with the disease in question because health assessments made by the participants can differ from what is reported by healthcare professionals (Woodend, Nair, & Tang, 1997). In another systematic review, Neelakantan et al. (2004) assessed the quality of QOL instruments used in CPP research. Although the QOL questionnaires complied with quality criteria assessing measurement properties, they showed poor face validity. Neelakantan et al. (2004) emphasised that the development of new questionnaires must retain sound measurement properties while also focus on what is considered important by patients with CPP.

Findings from the qualitative study discussed in Chapter 4 discuss how women with CPP are impacted by their pain in great depth. These findings were used to develop initial items for a new CPP measure. Because the items have been based on interviews with women with CPP, it is expected that the questionnaire would have high face validity. This is because the items are expected to tap into topics that the women themselves consider important to their QOL, such as the impact of CPP on their relationships, sexual functioning, and psychological wellbeing.

In summary, there is no existing measure that assesses the impact of CPP in women's lives that is suitable for women with different conditions. A new CPP measure could be used to reliably compare data across studies that include women with CPP.

Study aim

The aim of the current study was to develop and pilot a new questionnaire that assesses the impact of CPP on women's lives. This questionnaire will allow for more standardised comparisons between research studies and provide a means to systematically assess women-centred outcomes of interventions. The development of the questionnaire was informed by findings from the qualitative study discussed in Chapter 4, as suggested by previous research (Jones et al., 2002), as well as by a review of previous questionnaires. The

questionnaire was designed specifically for women with CPP and assesses issues they consider relevant and important to them.

Method

Questionnaire development

In Chapter 4 a qualitative study was conducted that aimed to explore the impact of CPP on women's lives. One-to-one interviews were conducted with 25 women who experienced a variety of CPP conditions, including IBS, vulvodynia, endometriosis, and neuropathic pain. Data were analysed using thematic analysis (Braun & Clarke, 2013). The main themes included problems with general functioning (feeling fatigued, problems with socialising, exercise, hobbies, and planning), not being able to talk about the pain, negative experiences with the medical system and health professionals, not being able to work, negative emotional consequence of the pain, relationship strain, pain with sexual intercourse, and negative financial implications of the pain. The development of the questionnaire was informed by the qualitative data obtained from these in-depth interviews. The first stage of the questionnaire development involved selecting the constructs to be measured, which was based on the main themes obtained from the interviews. These selected constructs formed the questionnaire domains:

- Daily functioning (e.g., everyday activities; fatigue; planning)
- Ability to work with CPP (e.g., sick days; productivity at work; feeling judged at work)
- Social functioning (e.g., does the woman feel people are not interested her pain; has the individual lost friends because of her CPP)
- Cognitive and emotional impact of CPP (e.g., suicidal thoughts; impact on self-esteem; anxiety; depression)
- Impact of CPP on personal relationships (e.g., sexual pain; perception of sex; ability to have sex; ability to talk about the pain with partner; ability to engage in activities with partner)
- Financial strain

- Positive outcomes (e.g., pain had helped to become emotionally stronger; more understanding of others)

After finalising the chosen constructs, the questionnaire items were generated based on these domains and the interview transcripts from the qualitative study. Items were carefully written and selected to reflect what was discussed in the interviews from the previous qualitative study. Item generation and development followed the principles outlined in Sudman and Bradburn (1982). The questionnaire items were revised based on feedback from research supervisors. Feedback included comments on how questions were phrased, the ordering of the questions, and removing unnecessary items, which resulted in 72 items. This helped ensure good content validity. Likert-type scaling was used for the response format (Likert, 1932). The responses were on a five-point scale indicating the level of impact of CPP within each domain. Items within each domain can then be summed to give a total domain score. A likert-type scaling method was used because such scales are quick, efficient, easy to understand, easy to code, and allows the participant to respond along a continuum (Kothari, 2004). Think aloud interviews (Charters, 2003) were conducted to obtain feedback from women with CPP on the draft questionnaire. The questionnaire was then modified according to the feedback obtained from the think-aloud interviews (see Tables 5 and 6 in Appendices U and V respectively).

Participants and recruitment

Women were eligible to take part if they were at least 18 years of age, and were experiencing CPP for a minimum of three months. Ten women were recruited to pilot the questionnaire using think aloud interviews (Charters, 2003). Think aloud interviews require the participant to say what they are thinking out loud to gain insight into their thought processes (Someron, Barnard, & Sandberg, 1994). In this study, participants said out loud what their thoughts were as they read through the questionnaire.

The study was advertised in a variety of organisations/. These included the following local newspapers: Daily Echo; Portsmouth News; Basingstoke Gazette; Andover Advertiser; Romsey Advertiser; Bournemouth Echo; and Hampshire Chronicle. The following charities were also contacted: Pelvic Pain Support Network, Vulvar Pain Society, Pain Concern, Action on Pain, Pain Support, Verity, and Endometriosis UK. Four out of the seven charities agreed to advertise the study on their website. One charity invited the researcher to attend a

support group session to discuss the study with the attendees in person. The study adverts consisted of a brief explanation of the study, including the study aim, confidentiality information, and a contact email charities (see Appendix K). Women were able to volunteer by emailing the researcher if they were interested in taking part.

Women who contacted the researcher were screened to ensure that they were at least 18 years old and they had experienced CPP for a minimum of three months. This was done by email and again in person when they met with the researcher. Other background questions were asked to gain more understanding of the participants' pain history (see interview guide in Appendix P). These included the following:

- When did the pain start?
- Where is the pain?
- How does the pain feel?
- How long have you experienced your pain?
- Have you seen a doctor?
- How frequently do you feel pain?
- How long does your pain last?
- What investigations have you had?
- Are you taking any medication for your pain? Which ones?
- What else are you trying/have tried to make you feel better with the pain?

Measures

The questionnaire that was developed and piloted was called The Impact of Female Chronic Pelvic Pain Questionnaire and initially consisted of 72 items (See Appendix Q). Demographic information was also obtained at the start of the interviews using a demographic questionnaire consisting of nine items (see Appendix R).

Procedure

A total of 10 women with CPP were recruited to attend a face-to-face think aloud interview. Interviews were arranged at a time convenient to the participants and were held in a private room at the University of Southampton. Interviews took place between 9:00 and 17:00 hours and were audio recorded with the participants' consent. Consent was always

obtained at the start before the interviews commenced and after the participants had read through the study information sheet (see Appendices K and L). The pilot interviews were audio recorded so that the feedback could be easily re-accessed during data analysis. During the interviews, participants read through and provided their feedback on the questionnaire items. Feedback was also obtained to ensure the questions were clear, to reduce the number of items by deleting repetitions, and to eliminate items that were not relevant to the impact of CPP. A checklist of questions was used during the think-aloud interviews (see Appendix P), which included the following:

- What did you think of the questionnaire overall?
- Is there anything you liked about the questionnaire?
- Is there anything you didn't like about the questionnaire?
- Did you feel you were able to understand the questions?
- Did you feel comfortable answering the questions?
- Were the questions worded in a clear way?
- Are the answer choices compatible with your experience?
- Are any questions very difficult to answer?
- How did the questions make you feel?
- Is the questionnaire too long?
- Are there any other important questions that have been missed?

At the end of each interview, each participant were debriefed (see Appendix N) and were offered either four credits (if they were a University of Southampton student) or £8 as a thank you for taking part. Participants were required to sign a study receipt to confirm that they had received payment (see Appendix O).

Ethical issues

Ethics forms were submitted to the University of Southampton's Psychology ethics committee, which were approved before the study commenced. Some items asked personal questions, which had the potential to make the participants feel uncomfortable and experience some negative emotions. During this pilot study, however, participants were not asked to complete the questionnaire but instead give their feedback on the items. In addition,

participants were informed at the start of the study that all their responses would be made anonymous and that they could withdraw from the study at any point without giving a reason.

Data protection and anonymity

The study complied with the Data Protection policy of the School of Psychology at the University of Southampton. Participants were required to provide their names to indicate their consent for participating and to confirm that they have received their payment. Consent forms and receipts were separated from questionnaire data and kept securely in a locked office.

Data analysis

The audio tapes were transcribed verbatim by the researcher. Data analysis followed a thematic approach to identify themes or patterns of what the participants thought about the questionnaire overall (Braun & Clarke, 2006). Other qualitative approaches were not considered to be as suitable to analyse the data. An IPA would involve focussing on the perspectives of individual cases (Biggerstaff & Thompson, 2008). Although the current study included a relatively small sample, the aim was not to analyse and report on each individual case, but to identify patterns across the dataset. Grounded theory would not have been appropriate because this method involves constructing a theory from the data (Corbin & Strauss, 1990). Finally, discourse analysis is an approach used to analyse the use of language within specific social situations or a framework of social or cultural conventions (Braun & Clarke, 2006), which was not the aim of the current research. Instead, an inductive approach was used and analysis was data-driven and not based on any pre-existing coding frame. The transcriptions were initially read carefully to identify meaningful comments made by the participants. Meaningful texts were coded, which were then grouped together into themes. Some codes were grouped in more than one theme. NVivo 10, a qualitative analysis programme, was used to analyse the transcripts (QSR International Pty Ltd, 2012).

Results

Table 5 (Appendix S) provides the participants' demographic information. The Results section is presented in two parts. The first part will discuss the main themes and subthemes from the think aloud interviews. The second part of the Results section will present changes that have been made to the questionnaire as a result of the think-aloud study.

Part 1 – Main themes and subthemes

“PPT” is used to indicate the participant, followed by the participant number, the diagnosis, and the page and line number of the extract. The use of “I” indicates the interviewer. The use of “P” indicates the participant when the extract consists of a dialogue.

Figure 3 (Appendix T) presents the thematic map. A total of five themes were identified. These were:

- Affective reactions (subthemes: ‘Negative feelings from questionnaire’; ‘Positive feelings from questionnaire’)
- Content (subthemes: ‘Positive comments’; ‘Questions perceived to represent certain groups’; ‘Time frame’; ‘Suggested questions’; Too much focus on relationships and sex’; ‘Questions that need adjusting’; ‘Specific items’)
- Length of questionnaire
- Questionnaire organisation
- Response options (subthemes: ‘Negative comments’ and ‘Positive comments’)

Affective reactions

A number of the questionnaire items elicited emotional reactions in some of the participants. Both positive and negative emotions were evident.

Negative feelings from questionnaire

A number of participants felt negative emotions when they read some of the items. For some women, these items were reminders of the impact of their pain and brought back negative emotions that were felt at the time. This was especially true for the items that asked about sexual activities. Other participants felt that questions 70-72 (70 – “I felt controlled by

my pain”; 71 – “I felt that my pain has taken away my life”; 72 – “I felt unable to cope with my pain”) were quite negative to finish the questionnaire with. This is highlighted by the following extract:

“P: umm.....I personally just, literally the last three questions make me feel very negative, and I thought oh god, do I have to think about, you know I have to think about, do I feel my life has been taken away and, what if I actually feel very strongly about that, and what if I end up going away having filled in this questionnaire and the last thing that I take away with me is, “yes this pain has taken my life away” and...sort of.....it kind of gets me down in a different way, whereas maybe before I was kind of feeling ok sort of fairly neutral and then you, you finish on a, ummm, on a, on a note that kind of...makes you feel down

I: ok.....

P: so you might, I mean if somebody feels really, really, really strongly, really badly, they might not want to be reminded just how badly they feel....

I: hmmm

P: ...at the end of it, to sort of, because that's kind of what sticks in your mind most somehow” (PPT8; endometriosis/ vulvodynia/ pelvic organ prolapse; Pg14, L505)

It was suggested that these questions be moved to a different part of the questionnaire so that the questionnaire ends with more positive questions. Other suggestions included re-phrasing these questions so that they are worded in a more positive way. For example, one participant suggested that question 72: “I felt unable to cope with my pain” could be changed to “I felt able to cope with my pain”.

Positive feelings from questionnaire

Despite the negative emotions experienced by some participants, a number of positive emotions were reported. Although the questions that asked about sexual activity had the potential to bring back negative emotions, some participants saw this as a good thing because it made them more aware of their feelings, which in turn was perceived as a way of facing and dealing with these negative emotions. This was also true for items that asked about the emotional impact of their pain (e.g., item 59 – “I felt irritable or snappy”) and some felt that answering such questions made them more aware of the emotions they experienced because

of their pain. For one participant who felt she was in control of her pain, the items elicited positive emotions because they asked about events that had happened in the past but which no longer applied. This allowed her to acknowledge how far she had come with her pain as she now no longer experienced much of the negative impact.

For a number of participants, the items seemed to reflect and cover most of the areas of their life that had been impacted by the pain. This resulted in feeling understood and as well, not feeling alone with what they had experienced as a consequence of their pain. Because many items were perceived to be relevant to their experience of CPP, several participants expressed how they felt the items validated their pain experience, which they found reassuring. The following extract illustrates this:

“P: to see peoples’ experiences and what I’ve felt, just amazing, and it makes you feel, you know what it makes you feel, it makes you feel validated, it makes you feel like you’re.....err, like.....its what a.....I don’t know, its like you’re....validated I think it feels like you’re, you know, what you’ve been through is real” (PPT4; Vulvodynia/ interstitial cystitis/ irritable bowel syndrome; Pg22; L760)

Content

Much of the feedback from participants concerned the content of the questionnaire. The feedback was quite varied and has been categorised into the following subthemes: ‘Positive comments’; ‘Questions interpreted to reflect certain groups’; ‘Questions that need adjusting’; ‘Time frame’; ‘Suggested questions’; ‘Specific items’; and ‘Too much focus on relationships and sex’.

Positive comments

Overall, the questionnaire was well received by the participants. The majority felt that the questions were generally clear and easy to understand. The women liked how the questionnaire included questions that asked about the emotional impact of their CPP as well as questions that they felt were not usually acknowledged e.g., item 4 – “I had problems sleeping because of the pain.” Many participants particularly liked the more positive questions (items 67-69) because they felt that these items brought out possible good outcomes of their pain experience. Other particular questions women liked included the items

that asked about the impact of CPP on communication with partners as this was seen as a common issue. Some participants commented that they thought the questionnaire would be a useful tool in healthcare and could be used to highlight issues to healthcare professionals. This was seen as a way to aid communication between them and healthcare professionals about the impact of their CPP so that they could receive the help they need.

“I: alright then, thank you very much, um is there anything else you wanna add, to...any comments? Anything else you wanna add?”

P: umm no, I'm, I'm, just that I think its good that it, the areas it highlights, so, yeah, I think its, I think it would be a useful tool, yeah, I think it would.....err, well, I don't know, they might not be using it, but if it was say for, in healthcare I think it would actually.....highlight things that.....health professionals may not think about...

I: mmm

P: ...which will be actually important, it can get missed so, I think its good, in that sense, and in any sense (both laughs), so yeah” (PPT7; endometriosis/ pelvic adhesions; Pg22; L733)

Some participants noted that some women may not be as open about their pain as others, especially when it comes to the impact of CPP on sexual functioning. Nonetheless, the questions were perceived to be appropriate especially if confidentiality was maintained.

In general, participants felt that the questionnaire was quick and easy to complete because no writing was required from them. Many women also liked that the questionnaire covered many different areas of life that had been impacted by their pain and thought that the questionnaire was very comprehensive. Participants stated that the questionnaire demonstrated understanding of their CPP because the questions were, on the whole, relevant to their CPP experience and included a variety of questions. Most of the participants thought that the questions were generally phrased well and were not offensive. Moreover, participants liked how the questions were to the point, were neutrally worded, and tended to use everyday terms e.g., item 47 – ‘I felt “fobbed off” by my doctor or health professional’.

Questions perceived to represent certain groups

Although the items in the questionnaire were intended to represent all women with CPP conditions, some participants felt that some items were not as representative as others.

For example, a small proportion of women thought that some items were biased towards heterosexual relationships and excluded homosexual relationships (e.g., item 22: “I worried that my partner may satisfy *his* sexual needs with somebody else”). The use of the word “his” assumes the participant’s partner is male, which may not necessarily be the case. Moreover, the use of the term “sexual intercourse” was perceived to be heterosexual orientated because it implies penetrative sex, which may not be relevant to women in homosexual relationships:

“P: ‘The pain has reduced my desire to engage in sexual intercourse’, this is more specific, cause its, asking about intercourse, not, not just any type of sexual activity, so, err, its like ‘I’m not currently engaging in sexual activities’ ag, again, making more specific with the partner, but then is it...heterosexual?”

I: sorry?

P: is it very heterosexual? Focused? Because if you think about two women having sex

I: yeah

P: it might be completely different” (PPT5; polycystic ovary syndrome; Pg15; L510)

One participant felt that some items in the questionnaire seemed to reflect those with a more serious health condition compared to her situation. For example, the items at the beginning of the questionnaire ask whether the pain had impacted everyday activities that are considered quite simple e.g., being able to sit, stand, or walk. Because such activities were not a concern for the participant, she perceived the questionnaire to be aimed at those with serious health conditions:

“P:.....the examples for me are a bit.....so they’re just from different categories so is being able to sit is a very basic thing, so it almost suggests for me that ok its for people, maybe its for people who are very very ill, not with just pelvic pain, but maybe that, because there’s some kind of very serious disability, and then it talks about hobbies and household tasks, so then the first thing that comes into my mind is.....is it, for anyone with pelvic pain, or is it just for the people who are, very very seriously affected by it

I: ok, is this from the intro?

P: yeah so in, in the intro because the examples like being able to sit for me, immediately got the association ok, this is for seriously disabled people who just you know, who are all the

time in bed because they are not able to walk or do anything so its, just like ok.....and then I would expect something very serious here

I: hmm

P:.....so, again it starts with this very, very serious, “I found it difficult to sit because of the pain” (PPT5; polycystic ovary syndrome; Pg1; L19)

Finally, a number of participants who were in current relationships felt that they could answer the questions aimed at women who were not in any relationships (items 35-40). Being in a relationship did not necessarily stop some of the participants from thinking about potential future relationships because of the possibility of a break up. Some of these items may also apply if the participant had entered a relationship within the last month. For example, in relation to item 35 – “I have avoided new relationships because of the pain” – a participant may have avoided the relationship she is currently in during the past month. In addition, it was suggested that some women may be open to future sexual relationships despite being in a current relationship:

“P: that's what I'm thinking....im finding, this (question 35) more difficult.....”

I: why do you think that's um, why do you think you find this one (number 35) difficult?

P:.....because.....(sighs), because its too two pronged I think, because A.....I would be....I wouldn't want to go there and experience the pain again.....but B, I'm not really interested in going there to try.....so I don't know how I would.....see that.....I currently am in a relationship but I wouldn't look, I wouldn't look for a sexual relationship again because A, that doesn't interest me, and B, or, or two As the pain, because of the pain

I: hmm. So the “not applicable because I'm currently in a relationship”, you don't think that will be.....

P: more applicable

I: hmm

P:.....yeah.....yep. “I have been worried that a potential new partner will not understand my pain”, I guess sorry yes, not applicable because I am in a current relationship, yeah, but just the possibil.....yeah, I don't want.....yeah, “I don't want to have to talk about my pain to a potential new partners”again, it is because I am in a current relationship, but I

don't.....i don't know if that would.....stop me, if I wanted to have a sexual relationship with somebody outside my relationship” (PPT4; vulvodynia/ interstitial cystitis/ irritable bowel syndrome; Pg14; L486)

Time frame

The questionnaire instructions asked participants to “think of the past month only” when answering the items. This was difficult for many participants. Some argued that a one month time frame may not provide a good overview of the impact of their pain because each month tends to differ, with some months being better or worse than others.

“P: I think for me.....if someone wants to know my experience from the last month its ok, but if someone is interested in my experience of chronic pain....

I: yeah

P:and how it affects my everyday activities, its very different from month to month, so.....

I: ok, so how would you recommend that it should be asked?

P: it depends on what you want to know, because if its just a doctor doing, I don't know, using this questionnaire every month just to see the dynamic of changes, because change of medication or activity or anything else, then this could be useful just to monitor the, the dynamic, but if it wants to see the general experience....err.....er over the month, especially that mine's specifically related to the cycle, it, it can be a very hard month, or it can be pretty good, its never very good, but it can be pretty good

I: uhm

P: so err, if I just complete this questionnaire month after month, then it can be completely different, there may be no consistency between that because it's a surprise for me if I have a good month” (PPT5; polycystic ovary syndrome; Pg5; L170)

In addition to inconsistent months, participants reported that some items asked about events that were difficult to answer in terms of a one-month time frame. For example, some participants found item 42 (“I have lost friends because of the pain”) difficult to answer as they may have lost friendships because of their pain beyond the past month. In such instances, participants would still want to agree with the question because they felt that it did

still apply to them. This was also true for the items that asked about sexual functioning. Some participants had stopped engaging in sexual intercourse for a number of years because of the pain, which meant that they had not engaged in sexual intercourse within the past month. This led to some difficulties with answering some of the items that asked about pain during/difficulties with sexual intercourse within the last month. Some participants answered the sexual items in relation their last sexual experience, which may have occurred years ago, rather than within the past month. In other cases, an event may have occurred relatively recently but not within the past month. This led some participants to disagree with these items even though they felt that such issues were still affecting them. This caused difficulties with answering certain items; participants tended to want to indicate that they had been affected by certain events even though they may not have occurred within the last month:

“P: ‘talk about my pain’hmmm hmmm hmm.....yes I think the question formats are alright, its just that umm, for these questions I'm thinking again about the one month time frame

I: ok

P: so if, if I haven't really talked about my pain during this past month, how would I answer this question ‘I felt people are fed up hearing about my pain’? so I mean, this is something I have felt, but, not this month

I: hmmm

P: so.....I um.....so yeah, if, if I would be answering this, with the month, one month umm, time frame.....I would feel I'm not able to talk about my condition because if some of, you know like this one (points to question 63), I umm, I talked about just, just now, if this one hasn't happened, I am not able to express that this has affected me and its still affecting me, so I would say, I don't know I would say ‘disagree’ to that one, but its actually err very much there, because it, I mean it still affects me to this day of how I will talk about it, and how I talk about it to, even to people who.....you know they know what I have, and, to, you know to people who have seen me in pain, its still difficult to, to tell them that because, people they might just.....err get fed up and even if they're not, I might feel like they are, so it, it this has affected me but.....yeah I can't I can't really, umm.....express it now that I have to talk about this past month” (PPT1; endometriosis; Pg18; L620)

Some items were seen to ask about more general feelings that were difficult to think about in terms of the past month. The following extract highlights this with regards to item 67 (“My pain has made me emotionally stronger”):

“P: ...the emotional growth its something that happens over the month like.....is it very....specific for the last month, something happened and it make you...made you feel emotionally stronger, or just.....I would say its more....to the general exp.....its more relevant to the general experience of pain, rather than pain in the last month” (PPT5; polycystic ovary syndrome; Pg35; L1216)

Furthermore, the one-month time frame created some issues with answering items 46 (“I felt frustrated because treatments have not worked”) and 47 (“I felt “fobbed off” by my doctor or health professional”). This is because, although participants tended to agree with these items, they may not have necessarily been to see a health professional within the past month and in some instances, had not had any treatments within the last month. This was more the case with the women who were more recently diagnosed with their CPP or had not yet received any diagnosis. The items that were not as affected by the one-month time frame were the ones that asked about physical functioning e.g., item 1 (“I found it difficult to sit because of the pain”).

The one-month time frame was not something that stuck in all the participants’ minds when answering the questions and it was not uncommon for them to forget halfway through the questionnaire that the items were asking specifically about the past month only:

“P: I supposes its me being absent minded, I forgot by the time I got to 46 that you’d asked about the month” (PPT6; no diagnosis; Pg4; L101)

When participants were asked what time frame they would prefer or what would they recommend for the questionnaire, there were some varied responses. Some participants suggested expanding the one month time frame to three months and/or six months. Others suggested the inclusion of reminders on each page which reiterated the questions concern the past month only.

Suggested questions

During each interview, participants were always asked whether they could suggest any other questions that were not included in the questionnaire. A number of suggestions were made, with the most frequent being to include a question to assess the participants' level of pain. Although it was made clear that the aim of the questionnaire was to assess the impact of their CPP, rather than how much pain they were experiencing, a number of participants wanted to communicate their level of pain in some way. For some, expressing the intensity of their pain is how they would communicate the impact of their CPP condition in the hope that it would be taken more seriously by others:

"P: ...I would add, communicating how painful my pain is.....because no one really disagrees I mean, I've, I've read somewhere that endometriosis pain is like umm kidney stone pain, I haven't had a kidney stone ever, thankfully, to compare with, but when I explain it to people, I ask them if they've ever had a kidney stone, and if they say yes, I tell them that's how it feels, and with those people, I've said that, I've seen very different reactions like 'oh', suddenly they realise that what they've been through once with the kidney stone, I have to go through like every month, so.....resorting you know, to this kind of comparison when I'm able to.....is, you know is, it is a good thing because I'm able to communicate it somehow to those people, but with most people, I'm not, because I will tell them, 'yeah, its, it's period pain, it's really, really extreme' and yeah other women will tell me 'oh yes, I've got very painful periods as well and.....I mean, unless they tell me about their periods.....and I sus..I suspect that they might have endometriosis as well, in which case I tell them, you should go check that because it is important. If its not the case, I'm not really able to explain to them that, you know my pain, it's very different from yours, I totally understand that periods are painful in general but.....they should not be the way they are with me

I: hmm

P: so communicating the.....intensity of pain, is really really hard for me to do, I mean, in general how it feels in my body, maybe because it is associated with an already existing pain? So yeah as I said err women will tell me 'yep, I get really painful periods as well', er yeah that moment I know, its not the same pain, but I can't explain it

I: ok, so you want a question on communicating the pain?

P: communicating the intensity of the pain, and err how it feels in general, because umm.....I'm guessing that....yeah it's a, it's a different, yeah it's a different kind of pain, in the way it feels in your body, which yeah it, it's not that important how it feels but, I think the

intensity is what is most important and.....I don't really know how to do that” (PPT1; endometriosis; Pg22; L762)

Other participants suggested including items that compare the pain at its worse with how it is currently. This was suggested because it would demonstrate to whoever is interpreting the questionnaire whether the participant’s pain had improved or worsened. Another reason for suggesting items that compare previous pain to current pain was to provide an overall picture of how the pain varies over several months. In both instances this was seen by participants as being reflective of the impact of their CPP.

Other suggestions made by some participants were to include more items that assess the impact of the pain on occupational functioning. There were two items that assessed the impact on work: items 13 (“I took time off work because of the pain”) and 14 (“The pain has negatively affected my performance at work”). Although participants were generally happy with these items, it was felt that these two items alone did not adequately cover the impact of their pain at work. Women suggested including items that asked about the relationship with bosses and co-workers and whether they had been misunderstood or experienced difficulties discussing their CPP at work. Other suggestions included adding questions on: cancelling plans because of the pain; people close to them not taking the pain seriously; the impact of the pain on spending time with children and family; problems with concentration because of the pain; the relationship with doctors and whether the pain has been dismissed as a woman’s issue; whether the pain has held them back in life; pain with orgasm; side effects of medication; loss of appetite; “wanting to lie down” (as well as item 8 “had to lie down”); and not being taken seriously by the doctor (as well as item 47 – I felt “fobbed off” by my doctor or health professional).

Finally, a small number of participants wanted more “positive” questions. There were three items that assessed positive consequences of the pain: items 67 (“My pain has made me emotionally stronger”), 68 (“My experience of pain has motivated me to help others with similar conditions”), and 69 (“My pain has made me more understanding of others with similar conditions”). Suggested questions included adding a question on whether the pain had made the relationship with their partner stronger, on whether they had accepted their pain, and whether the pain had become a part of everyday life, and whether their pain had made them more understanding of others in general (i.e., not just understanding of others with similar conditions, as is stated in item 69).

Too much focus on relationships and sex

Although CPP conditions can have significant negative effects on relationships and sexual functioning, this is not always the biggest problem. One participant felt that the questionnaire had a disproportionate focus on the impact of CPP on personal relationship and sexual intercourse compared with the other areas of life so that she had almost forgotten that the questionnaire was not just assessing relationship satisfaction:

“P: ...and at this stage, I got a feeling it's a questionnaire about my relationship, not about the impact of pain...

I: uhm

P: ...anymore, the first questions were about pain, and they were just focussed....these ones I just feel they are more asking me about the quality of my relationship rather than err the impact of pain, on the relationship, it may be just my.....focus, and how I see them, but its just like, I almost forgot, its...I think the balance between the questions, and I feel like, ok this is a lot about the relationship and the sex in the relationship but....like for me personally, my pain affects.....many other areas much more than this, so then its just like ok, this is all just one area that can be affected and the others are just mentioned at the beginning and then its all a huge part of the relationship

I: uhm

P: so I feel like it's a bit too much about relationship comparing to other.....other things.”
(PPT5; polycystic ovary syndrome; Pg21; L715)

This participant expressed how she was aware that a lot of the relationship and sexual satisfaction items would have been applicable to women who were in new relationships. However, because she was in a long-term, stable relationship, these items were not seen as relevant to how she felt in her relationship. In addition, there are a number of items dedicated to assessing the impact of CPP on relationship functioning and sexual satisfaction, which seemed biased towards this area of life:

“P: ...I suppose if it is applicable....this would be the part that someone will have a lot on their mind, if you're searching for a partner, like, at the beginning so the.....the, the first questions, the, they, they, quite a lot depend on if you're just in a brand new relationship, where not everything is disclosed, or if you're in a very long term relationship, and this is

like....its completely the area that you don't think about if you've got a steady partner, so just like....even reading through the questions just, make this err.....its a completely different situation it, er, makes this impression that its, all about sex in the relationship and not about your pain” (PPT5; polycystic ovary syndrome; Pg22; L736)

Questions that need adjusting

There were a number of items that some participants felt were not relevant to their experiences of CPP. A few items were seen as asking about issues that were not necessarily exclusive to women with CPP conditions. Some items were perceived to be unclear and some appeared repetitive.

The items that were most frequently highlighted as being less/irrelevant to women with CPP were items two (“I had difficulties with wearing tight-fitting clothes”) and 65 (“The cost of buying new comfortable clothes has been difficult to deal with”). Some participants felt that these items may not be relevant or exclusive problems for women with CPP. One participant stated that she had not really thought of buying new comfortable clothes as being a problem and tended to look for comfort in clothes in general. Another stated that she would have preferred a “not applicable” response option available because she thought question 65 was not relevant.

Other questions that were seen as less relevant were items 22 (“I worried that my partner may satisfy his sexual needs with somebody else”), 29 (“Sex has become a “task” that I engage in to fulfil my role in my relationship”), and 32 (“Foreplay (sexual activity not involving intercourse) feels disappointing”). These items were perceived as being not necessarily related to the pain but about how secure, and how sexually satisfied, participants felt in their relationships with their partners.

A number of items seemed to be asking similar questions, which came across as quite repetitive to some participants. The specific items that were perceived to be very similar were items 17 (“I struggled to talk to my partner about my pain”) and 20 (“I have had difficulties communicating with my partner about my pain”). Participants tended to prefer item 20 to item 17:

“P: “I struggled to talk to my partner about my pain”yeah, “I felt closer to my partner because of my pain” “.....put a strain in my relationship”yeah

they're all clear err..... "I've had difficulties communicating....." that ones similar to 17 isn't it? Is that....?

I: ok

P: but sometimes they do that don't they? Just to make sure....

I: do you think they are similar?

P: I would say they are.....

I: ok

P:quite similar

I: right.....is there one you think is clearer or.....

P: umm.....probably.....yeah probably, maybe.....the second one, "I had difficulties communicating with my partner about my pain" (PPT6; no diagnosis; Pg2; L50)

Two other items that were also frequently seen as very similar were items 11 ("I felt tired because of the pain") and 12 ("I felt my energy levels were low because of the pain"). Out of these two items, participants tended to relate more to item 12 compared with item 11:

"I: its more how you would interpret it, so, if you were gonna answer these questions, how would you....approach them?"

P: I prefer this one (points to question 12).....

I: prefer this one?

P:.....to that one

I: any reason?

P: errr, I don't know, it just feels more.....umm, 'tired' is quite a loose.....err word, like it could be.....umm if you were feeling sad, you might say 'oh I'm just feeling tired' sort of thing, like, you know, like what you find with depression and that sort of thing, they, they tend to say 'oh I'm tired' when really its not, that they haven't had a sandwich, or that they haven't slept its just.....emotionally they are feeling, drained, ummm whereas 'energy levels', its more that the pain has physically taken your muscles and energy to sort of you know, to

move and contract, you know, you are physically lacking in, in energy, so I don't know, for that (points to question 12) I, I would say physically that's tired, but that (points to question 11) could be physically or emotionally tired so... um yeah, that's probably why I'm not.....

I: ok

P:I'm not getting that one (question 11). ” (PPT2; no diagnosis; Pg4; L107)

There were a number of items that participants felt were not clear and led to many participants asking the interviewer for clarification. These items needed addressing especially because it is intended that the questionnaire be completed alone without supervision. Items that needed clarification tended to be ones that did not have any explicit reference to the pain (e.g., item 54 – “I have gotten upset easily”). Because it was clearly stated at the start of the questionnaire that the questions concern the participants’ CPP, it was expected that not all the individual items themselves needed to refer to the pain. Nevertheless, a number of participants wanted such items to be clarified and given context by ensuring they refer to the pain:

“P: err, so “I felt sad....”, “I felt unmotivated”again I wouldn’t be afraid of adding its because of the pain, because if its just sometimes because of the pain and sometimes without, I...then I’ll be just thinking ok are you asking me about the pain or just generally? Some have it, and some don’t, so its confusing...” (PPT5; polycystic ovary syndrome; Pg31, L1066)

“P: ‘I have gotten upset easily’yeah, I think this might be like a con...umm, like, you might wanna know..... ‘I’ve gotten upset easily because of....’, because of the pain, because my partner is not....happy with my pain, cause of.....work is....rubbish because of the pain, yeah just a bit of context would be good,” (PPT2; no diagnosis; Pg13; L437)

Specific items that were unclear to participants included item 32 [“Foreplay (sexual activity not involving intercourse) feels disappointing”]; this item seemed to be misinterpreted a number of times, though was not always flagged up as being unclear. It appeared that some women interpreted the item to be asking about pain during foreplay, when actually the item intended to refer to feeling disappointed at foreplay because of not leading on to sexual intercourse (because of the pain):

“P: umm.....‘foreplay feel disappointing’, err disagree, its only actual intercourse that umm causes the pain so um, that’s fine,” (PPT3; adenomyosis; Pg6; L188)

For other participants, item 32 seemed to be asking about relationship or sexual satisfaction and not necessarily in relation to CPP:

“P: I’m surprised, like you could say it felt disappointing because my partner was not good! (laughs), and it does...it just doesn’t take... it doesn’t put a category of pain immediately, in your head, so although it is there in the context, we, so far from the questions that were asking about the impact of pain on the...every day activities, its so much about the relationship now, so it just takes your mind far, far away from the pain topic and.....yeah,

I: so its asking you more about.....

P: the quality of the relationship rather, rather than.....

I: rather than the pain

P:pain yeah,” (PPT5: polycystic ovary syndrome; Pg18; L606)

Other specific items that need clarification included items 10 (“I have avoided travel because of the pain”) and 44 (“I have felt socially anxious because of the pain”). A few participants were not sure about the type of travel that was referred to in item 10. Some participants were able to travel short but not long distances and were not sure how to respond to item 10. A small number of participants were not familiar with the term “socially anxious” and would have preferred wording such as “I have felt anxious socialising with other people...”

Specific Items

There were specific items that were frequently commented on by participants. These will be discussed in turn and included the following items: 48 (“I have had thoughts about ending my life because of the pain”; (“I took time off work because of the pain”); 14 (“The pain has negatively affected my performance at work”); 16 – (“I felt pressure to be a “normal woman” in my relationship with my partner”); and 33 (“Not being able to have sex has made me feel less of a “real woman”).

Although no participant had any problems with the wording of item 48, it was frequently reported that this item may be a difficult question to answer because of the potential of triggering an emotional response. In addition, for some participants it was a shock to read and they felt that it was quite a strong question. Because of the emotional

nature of suicidal thoughts, it was suggested that this item may not be answered honestly, even by a participant who had experienced these thoughts:

“P: I think some people for some of those questions would feel a bit more uncomfortable doing that, but I guess if it was anonymous then, yeah, then...umm, that would be fine.....the potential...it will be....umm, ‘I felt like ending.....’, was it? ‘felt like ending my life?’”

I: yeah

P: that one, potentially people might not put that, cause it might bring back.....like bad memories and things, but other than that.....yeah.....” (PPT3; adenomyosis; Pg14; L476)

Many women expressed some issues with the work items (13 and 14), with the main issue being what was meant by “work.” Some participants were university students, were volunteers of a charity, or worked from home. For these women, it was not clear whether these items are applicable to them or not. In addition, the fifth response option stated “not applicable because I do not work outside of the home,” which was confusing for participants who worked from home because it implied that these items were not relevant to them. When participants were questioned on how they would naturally answer these items, they stated that they would include unpaid work as well as education but that this was not clear when reading the items. Moreover, one participant was not sure about the type of time off item 13 was referring to:

“P: err you had the first questions are not being able to sit, not all work you can do lying in bed, so if I can read or write something lying in bed its fine, but if I had to sit on a computer, its, no way am I going to work, so then again, again, agree is... sometimes its just hours.....sometimes I take a day off and then I catch up on weekends, so....ok I took some days, time off work, so is it the question about.....doing breaks at work, or taking official time off work?”

“I: hmm, so you're asking if its taking time off work officially...or....

P: yeah, so like you're going off sick, you've got the certificate completed etcetera, and you didn't come to work completely...or did you need more breaks at work, so for example you said I've worked eight hours, you worked for five hours and then the next day you catch up or something

I: oh ok

P: cause I think that more people are now working flexibly, it will be really hard to say cause they may have, never over the year have any days off work, but you adjust your work pattern so there are days where you work more, and there are days where you work less because of the pain

I: ok I see, mmm

P: so, I would say yeah, I agree, I sometimes have to make a break, or I don't work for a day, and then the next day I work more hours just to catch up with the hours, but I don't have official days off work because I still do my work at the end of the week, so all the hours are done" (PPT5; polycystic ovary syndrome; Pg6; L206)

A number of participants expressed some thoughts when they read items 16 ("I felt pressure to be a "normal woman" in my relationship with my partner") and 33 ("Not being able to have sex has made me feel less of a "real woman"). Women generally felt that they were able to relate to these items and agreed that not being able to engage in sexual activities had impacted how they felt as women, though definitions of "real/ normal woman" were not consistent with all participants. For some, a "normal woman" was someone who did not experience pain and was able to get on with her usual everyday activities. Participants tended to be happy answering these items according to their own definitions of what they felt "real/ normal woman" meant for them:

"I: " I felt pressured to be a normal woman in my relationship with my partner", you said you liked that question, what reason did you like it for?

P: you haven't tried to.....over explain what you mean by real woman, by a normal woman, you've let that be.....what, I think.....but its gonna be different for different people, what a normal woman is, but instead of try and go, instead of being like oh I felt like I couldn't satisfy this, about my partner and this and this and this, and I felt like I couldn't do this, I thought I liked it cause it was quite general" (PPT6; no diagnosis; Pg8; L244)

Conversely, a small number of participants had some issues with these items. These participants seemed to agree that these items reflected some element of truth and that some women may feel less of a "real woman" because of not being able to engage in sexual activity with their partners as well because of their experience their pain in general. However,

these women argued that including such questions supported the notion of a “real woman” and their expectations of them as women in relationships, which came across as quite offensive. This may lead some women to start questioning whether they are “normal” or “real” even though this may not have been an issue to begin with:

“PPT1: ...I mean why, why would I be annoyed with this question is that ‘not being able to have sex has made me feel less of a “real woman”, is because I... ..i don't feel pressured to feel like a real woman, but it has made me question if I'm normal and if I'm like someone else and why can't I be like someone else, so I wouldn't want to answer ‘agree’ to that because, that's not something I care about, but I have cared about thinking.....am I normal and.....(PPT1; endometriosis; Pg14; L465)

Finally, a small number of participants expressed that the questions that asked about sexual functioning were likely to be difficult to answer by some women because of the personal nature of the topic. Despite this, these women stated that such items should not be removed for this reason because although some participants may feel uncomfortable, it is likely that they will be able to answer them and in addition, it was considered important to include the sexual functioning items to fully assess the impact of the women’s CPP:

I: ok, and er did you feel comfortable answering, I know you didn't answer the questions but if were gonna answer them, do you think you would have felt comfortable?

P: yeah, yeah, yeah I think I would have umm, I think like, the sexual activity ones, some people might be more....like nervous about answering them, cause its quite personal, but then.....something like pelvic pain is quite like personal anyway, so, they're more than likely to give in and just and answer it freely anyway, but.....a little bit of discomfort but, you know, its probably worth it if you're gonna be able to diagnose them better, so, no I think that was fine, I think it was good” (PPT2: no diagnosis; Pg18; L611)

Length of questionnaire

Most of the participants felt that the questionnaire was too long and that the length may be off-putting for some. However, participants found it difficult to provide suggestions to shorten the questionnaire because they felt that most of the items were very relevant to their experiences of CPP. Suggestions that were made consisted of removing some of the items that asked about emotions as some questions seemed quite similar:

“P: so like.....umm, the ones about feeling sad

I: ok

P: there's also ones about.....umm.....being angry, sad, mot...unmotivated, whether...getting upset easily....

I: uhm

P: I dunno whether they can be condensed into less questions, I don't know, but they...some of them see.....are fairly similar to each other, just at the end.....just the end ones of those.....umm.....like despair, unmotivated, sad, I don't.....for me, they all seem to roll into one so I don't know whether they can be.....just..to....to lessen the number of questions really, cause I think some people.....sometimes you can get something like this and you think.....halfway through you think ohh I don't wanna do it anymore (laughs)” (PPT10: vulvodynia/ irritable bowel syndrome/ pelvic organ prolapse; Pg9; L277)

On the other hand, a few participants were happy with the length and would not want to cut any of the items. These participants indicated that they would prefer to be given enough time to complete the questionnaire than remove any of the items and that completing the questionnaire should take as long as it needed to take.

Questionnaire organisation

Although the items were arranged into categories, the questionnaire was not officially sectioned by topic and the questions were presented in one block of 72 items. Some participants felt that this led to abrupt changes in topic and suggested creating headings for the different categories of items. For instance, items 36 to 40 include items that ask about the impact of CPP on how women approach potential future relationship, but then item 41 moves on to the social impact of the pain. Some participants would have preferred headings so that they could be mentally prepared to answer questions about certain topics.

“I felt frustrated because treatments have not worked”oh I see now, I would like to see categories, in this questionnaire, because it just takes your mind like to....err usual activities, then there's this huge part about relationship, then its about the social contexts and then suddenly treatment, and its like oh ok, the, the, the surprise is there.....and then suddenly they're changing topic...” (PPT5; polycystic ovary syndrome; Pg25; L870)

Another reason suggested by some participants for creating headings to categorise the questions was to skip over items that were not applicable. This was mainly in relation to the items that targeted those in a relationship and those who were not in a relationship. When the questionnaire was presented to participants in the think-aloud study, those who were not in a relationship still had to read through all the items that were intended for women in a relationship and vice versa. Some participants felt this was annoying and suggested including headings that allowed them to move on to the next section if the items were not applicable to them. One participant, however, stated that it may be best not to create headings because, as discussed above, some women in relationships may want to answer some of the items intended for single women.

Not all participants suggested creating subheadings; some instead recommended changing the order of the items to improve the flow of the questionnaire. For instance, one participant suggested re-ordering some of the initial questions so that the items about sitting, standing, and walking (items one, five, and six, respectively) were grouped together:

“P: ‘I experienced problems walking because of the pain’hmm ok, so I’ve just jumped ahead a little bit but.....you’ve got umm....you’ve got, ‘staying in bed and lying down’like separated by the ‘holidays’, maybe I would have put it.....either with the ‘sleeping’

I: hmmm

P: than the ‘walking’ or the ‘standing’? so that it sort of, is more, like in a similar, like section

I: hmmm

P: does that make sense?

I: yes, yeah

P: umm, but then, you might wanna mix them, I don't know, umm but it just felt like those were, sort of, in the same sort of area, the ‘walking’ and the ‘standing’ at least

I: ok, so sort of like a, the same category of the group, grouping.....

P: yeah, yeah, so like the 'bed' and the 'lying down' and then like moving on to the 'standing' and the 'sitting' and the 'walking', umm that sort of thing. Umm.....yeah, that's probably, how I'd, I'd do it umm" (PPT2: no diagnosis; Pg2; L54)

Another participant suggested moving the items about social functioning so that they appeared before the items about relationship and sexual satisfaction. This is because the relationship and sexual satisfaction items were seen as quite personal questions and it would be easier to initially answer items that were not so personal:

"P: ...where it goes back to social events and...41, I was wondering whether that kind of.....could of followed on from umm.....cause there was something at the beginning.....I guess its kind of, the question relating to the partner should come first and then...potential partners, and then, then social so.....um.....I wonder whether the social bit could come before you go into partnership because partnership is maybe the more intimate bit, whereas things like.....your work or maybe your social life is more.....initially its sort of easier for people to kind of sort of open up and start talking about it, than um about more intimate bits like oh, you know "I'm really worried about having pain during sex", for some people it might be easier if they answer the social questions first and then come to the more intimate umm, questions" (PPT8; endometriosis/ vulvodynia/ pelvic organ prolapse; Pg6; L196)

Response options

The response options that were presented to the participants consisted of a 5-point Likert type scale that ranged from "strongly disagree" to "strongly agree". Many comments were made regarding the response options, which have been grouped into the following subthemes: 'Negative comments' and 'Positive comments'.

Negative comments

The main issue that participants experienced with the response scale was not being able to indicate how often they had experienced CPP problems within the past month. Many participants expressed that they would have preferred a scale that contained "frequency" type wording (e.g. "all the time", "sometimes" and "never") rather than indicating how much they agreed with the items. When asked why, women stated that they would naturally think about their pain in terms of the number of days affected or about how much of a day was impacted

by their pain. This led to some participants trying to translate the frequency of problems experienced from their pain into how much they agreed or disagreed with the items:

“P: ... “I felt tired because of the pain”, this is clear and I think the same applies because sometimes I may and sometimes I may not so if its very often, or just occasionally, I, I I'm finding that my experience, there are months when its just occasionally it can be very few, and there are months when its just like, very often, so if I'm thinking about the last month, if it was a bit I would put agree, if it was a lot I would put strongly agree, but then I'm not sure if that's what the question is asking about, if.....

I: ok, but that's how you would fill it, if you were doing it

P: yep, but, but, then, its not clear for me, its my interpretation of the question

I: err you guessing, sort of thing

P: but that's how I would....because, then I'm, I'm trying to find a key, how to differentiate between agree and strongly agree or disagree and strongly disagree, so I suppose I would....just the severity and the frequency, I would think about these two and then on the basis of that, put agree or disagree, or agree or strongly agree

I: hmm

P: but I wouldn't feel very confident that, I gave the right answer” (PPT5; polycystic ovary syndrome; Pg5; L153)

This extract also highlights how the participant found it difficult to differentiate between “agree” and “strongly agree.” This is because the scale allows participants to rate the impact of their pain based on how they subjectively felt. As illustrated in the extract, this was problematic for some participants who were concerned about providing “correct answers.” Moreover, some participants were concerned with the thought that two people may score the same on particular items despite not experiencing their CPP in the same way. For instance, a participant may have taken months off work because of her CPP, whereas another participant may have taken three days off each week for a month. Both participants may tick “strongly agree” to item 13 (“I took time off work because of the pain”).

There were also some issues expressed with the “not applicable” response options. These not applicable options contained statements that provided reasons why certain items may not have been applicable. These were in relation to the work, relationship, and sexual

items. It was highlighted that in some instances, the response options “agree/ strongly agree” and “not applicable” may be relevant to some participants. For instance, participants may agree/ strongly agree with item 34 (“I felt frustrated at not being able to have sex”), but at the same time the “not applicable because I am not currently engaging in sexual activity” option may still apply to them if they are not engaging in sexual intercourse.

Positive comments

Despite the negative comments, some positive comments were also expressed. Some participants thought that the scale had a good number of response options which were clear and easy to understand. In addition, participants liked that the response options were consistent throughout the questionnaire as this made it easy to read through the items and saved time. Participants also liked the possibility of being able to choose a middle response option for items they were not too sure about:

I: ok, are the answer choices, responses, are they compatible with your experience?

P: yeah, I think so, yeah because umm.....I, as I said, I like the, having the umm....sort of err, having a neutral one and then.....

I: uhm

P:.....umm two intensities of agreement or disagreement either way, I think that's quite....intuitive” (PPT8; endometriosis/ vulvodynia/ pelvic organ prolapse; Pg15; L553)

Part 2 – Changes made to the questionnaire

A number of changes were made to the questionnaire as a result of the pilot study and discussions during supervisory meetings. Changes included deleting, combining, and clarifying the meaning of items. Table 6 (Appendix U) shows the items that have been deleted with reasons. A total of 22 items were deleted. Table 6 (Appendix U) highlights the items that were combined or edited to make them clearer.

A number of participants suggested changing the wording of the response options to reflect how often events have occurred. Despite this, it was decided that the same five point scale would be used in the final version of the questionnaire. This is because the aim of the questionnaire was to assess how the participants felt they were subjectively impacted by their pain rather than how often they had experienced problems. In addition, it was decided that the

items in the final version of the questionnaire will be presented in a random order rather than be grouped into categories. Randomising the items will mean participants are not focussed on a topic for too long before moving on to the next category of items. Finally, some participants would have preferred a longer recall period. It was decided that the one month time period would not be increased as this may negatively impact the accuracy of the participants' memory.

In response to participants' suggestions, three new items were added to the questionnaire: "The pain has stopped me from being able to spend time with my family"; "I have felt negatively judged at work because of my pain"; and "I have had problems with concentration because of the pain." These items were included in response to the qualitative feedback obtained from the participants during the think aloud interviews. The final version of the questionnaire included 52 items.

Discussion

Overall, the feedback from the participants was quite positive and the majority felt that the new CPP measure adequately assesses the impact of CPP. The majority found the questions to be clear, easy to understand, and thought the questionnaire would be a useful way of communicating issues to healthcare professionals. Many participants felt that the questionnaire was very comprehensive and covered most of the ways that their pain had affected them. Interestingly, the women tended to like the questions that asked about the emotional impact of their pain and generally felt validated by the questionnaire because the items were very relevant to their experiences of CPP.

Some participants discussed some aspects of the questionnaire they did not like and suggested some changes. For instance, some participants felt that the questionnaire tended to have too many items that asked about the quality of personal relationships and sexual functioning. To address this, 11 items were removed or changed to reflect the impact of pain on relationships and sexual functioning. This included items 16 ("I felt pressure to be a "normal woman" in my relationship with my partner") and 33 ("Not being able to have sex has made me feel less of a "real woman"), which some women found offensive. Another issue that was frequently discussed was the recall time period of the questionnaire. A number of participants would have preferred a longer recall period because of the inconsistency of their pain. Some participants said they would have "agreed" with certain items but because such events may not have occurred during the past month, they would have to "disagree"

with the item instead. This led to some participants thinking that their responses may not be a true reflection of their CPP experience. Although there is no golden rule as to what the recall period “should” be when assessing chronic pain, it was decided not to change the one month recall period. This is because increasing the reporting period can potentially lead to errors in pain recall (Broderick et al., 2008; Feine, Lavigne, Dao, Morin, & Lund, 1998). Moreover, recall accuracy has been found to be maintained at one month recall periods (McGorry, Webster, Snook, & Hsiang, 1999). In a study with patients from a community rheumatology practise, Broderick et al. (2008) assessed the accuracy of pain ratings for reporting periods ranging from one day to 28 days. Although a gradual decline in the correlation between momentary and recall ratings was found as the recall periods increased from one to seven days, the correlations for the 28-day recall were higher. It was discussed that this may be because patients with a chronic condition have beliefs that are based on their experiences with symptoms, which may lead them to have a good idea of their typical pain levels (Broderick et al., 2008). McGorry et al. (1999) also examined recall accuracy in a retrospective study with patients with chronic low back pain. The recall accuracy of pain was assessed at one week, one month, and six month intervals by comparing reports to daily pain diaries. Significant differences in recall accuracy were only found at the six month recall period and not for the one week or one month periods.

Some participants felt that the questionnaire moved too abruptly from topic to topic. Suggestions included sectioning the questionnaire by creating headings so that participants could be mentally prepared for the next set of items. However, it was decided that headings would not be created because there would be large differences in the number of items within each heading (which is especially true because of the reduction in number of items to 52). In addition, the creation of sections or grouping the items together may influence the participant’s responses to the individual items within each section leading to response bias. Tourangeau, Couper, and Conrad (2004) found that participants may assimilate or contrast an item with neighbouring items, which means response to an item may be affected by its physical position within the series of questions in this study. The items were more highly intercorrelated when they were presented together in a grid on a single screen than when the same items were presented on their own. Tourangeau et al. (2004) also found differences in response times with lower response times when the items were presented together in a grid. Participants were more likely to select the same answer and were less sensitive to the items that were reverse worded when presented together in a grid. It was concluded that participants used the proximity of the items to reflect their meaning and they were able to

read through the items more quickly at the possible expense of reading each item carefully. Therefore, the items in the next version of the questionnaire were presented in a randomised order.

There were a number of limitations in the current study. The majority of the participants were from a younger age group, with few women above the age of 50. In addition, all the participants were heterosexual and a significant proportion of them were students. It would have been useful to explore the perspectives of women from more diverse age groups, sexual orientations, and occupations on their thoughts on the questionnaire items. The women that took part, however, had a number of different CPP conditions, which meant that it was possible to explore whether the questionnaire items were reflective of the impact of different CPP conditions. Moreover, the study had a reasonable sample size, which generated very rich qualitative data.

As discussed, a number of non-CPP specific measures have been used to assess the QOL in women with CPP, including The SF-36 (Ware et al., 1996), the BPI (Cleeland & Ryan, 1994), and the PGWI (Chassany et al., 2004). Such questionnaires have shown poor face validity when used with women with CPP (Neelakantan et al., 2004). There are also currently questionnaires that have been developed to assess specific CPP conditions such as the EHP-30 (Jones et al., 2001), the Polycystic Ovary Syndrome Questionnaire (Cronin et al., 1998), and the ICSIPI (O'Leary et al., 1997). Nonetheless, a questionnaire that can be used to assess the impact of CPP conditions as a whole would be very beneficial. This is because CPP is associated with a number of different conditions, including endometriosis, chronic urinary tract infection, and IBS (Howard, 2003). In addition, many women with CPP do not necessarily receive a diagnosis of an underlying condition but are still impacted by their pain (Souza et al., 2011). A CPP questionnaire that is not specific to a CPP condition would also be useful in evaluating treatments that are not specific to a CPP condition e.g. pharmaceutical treatment, psychological therapies, and multidisciplinary interventions.

The findings from the current study have informed the development of the CPP questionnaire. The items were developed based on findings from the qualitative study and the questions reflect a number of areas of psychological wellbeing and functioning that have been impacted by CPP (See Chapter 4). Therefore, the new CPP questionnaire has good content validity. Furthermore, the pilot version of the CPP questionnaire was well received overall by the participants. Many felt that a new CPP measure would be a useful tool in healthcare settings. Questionnaire items have been either deleted or edited in response to the women's reactions and feedback. Feedback also led to the addition of new items. In the next

stage of this study, the validity and reliability of the CPP questionnaire were assessed in a sample of women who had experienced CPP for at least three months.

Chapter 6: The Development of a Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain

Detailed feedback on the IF-CPPQ was obtained in the think-aloud study presented in Chapter 5. This resulted in a reduction in the number of items and a clearer questionnaire overall with good face validity. However, the IF-CPPQ was still long with 52 items and its psychometric properties was still unknown. Because of this, a large quantitative study that aimed to assess the validity, reliability, and factor structure of the IF-CPPQ was conducted and is presented in Chapter 6.

Introduction

Chronic pelvic pain (CPP) is one of the most common pain conditions experienced by women and is associated with a number of conditions, including endometriosis, vulvodynia, and irritable bowel syndrome (IBS) (Abercrombie & Learman, 2012; Chao et al., 2015; Rosenbaum & Owens, 2008). Despite a high prevalence rate, ranging from 1.2% to 24%, CPP is still poorly understood and major difficulties in reaching a diagnosis are not uncommon (Ballard et al., 2006; Latthe et al., 2006a).

A number of studies have assessed the impact of CPP on women's lives. In a cross-sectional study, Tripoli et al. (2011) found that women with CPP had significantly lower sexual satisfaction when compared to healthy controls. In addition, women with CPP had significantly lower sexual frequency, greater sexual aversion, and a "lack of expression of sensuality" when compared to women without CPP. In another cross-sectional study, (Romão et al., 2009) found a significantly higher prevalence of anxiety and depression in women with CPP compared to a control group without CPP. In addition, the women with higher depression and anxiety tended to score significantly lower on quality of life. Indeed, psychological factors such as anxiety and depression have also been found to mediate the effect of CPP on sexual problems (ter Kuile et al., 2010b).

Though research has been conducted to evaluate the impact of CPP on women, there currently is no existing measure that is suitable for women with different diagnoses. As previously discussed in Chapter 1, the use of generic questionnaires has poorer face validity when administered to women with CPP and also has the limitation of not being sensitive enough to assess changes in HRQOL across a variety of diseases (Jones et al., 2002; Neelakantan et al., 2004), while the disease-specific questionnaires can only be used by

women with a clear diagnosis. It is common for women with CPP to not be diagnosed with an underlying condition and the pain has been considered to be a syndrome in its own right (Chao et al., 2015; Grace & Zondervan, 2006; van Os-Bossagh et al., 2002). A validated questionnaire that assesses how the QOL of women are being affected by CPP is needed to facilitate the interpretation and comparison of studies and compare data reliably (Quaghebeur & Wyndaele, 2013). In addition, when developing such a questionnaire, it is important to interview the population with CPP because health assessments made by participants can differ from what is reported by healthcare professionals (Neelakantan et al., 2004; Woodend et al., 1997).

In response to this need, the Impact of Female-CPP questionnaire (IF-CPPQ) has been developed and aims to assess the impact of CPP on women's lives. The items were generated based on qualitative interviews and have been piloted in think aloud interviews, in both instances with women experiencing CPP (Chapters 4 and 5). The aim of the current study was to assess the validity, reliability, and factor structure of the newly developed questionnaire.

Method

Participants and recruitment

To be eligible to take part, women had to have experienced CPP for a minimum of three months and be at least 18 years of age. A number of organisations were contacted to advertise and promote the study. These included the following local newspapers: Daily Echo; Portsmouth News; Hampshire Chronicle; Basingstoke Gazette; Andover Advertiser; Romsey Advertiser; and Bournemouth Echo. National UK Charities as well as charities based internationally were also contacted. UK based charities and organisations that were contacted included: Pain UK; Women's Health Concern; Pain Relief Foundation; Vulvar Pain Society; Verity; Pelvic Pain Support Network; Endometriosis UK; Pain Concern; The Cystitis and Overactive Bladder Foundation; and The IBS Network. Charities based in the Republic of Ireland included: Endometriosis Association of Ireland, and Chronic Pain Ireland. Charities based in New Zealand and Australia included Endometriosis New Zealand and Pelvic Pain Foundation of Australia, respectively. Finally, charities based in the United States included: the International Pelvic Pain Society; the National Vulvodynia Association; and the Interstitial Cystitis Association. Social media sites (Facebook, Twitter, and Linked-

In) were used to post study details. A number of Facebook groups were also contacted to post study information (Endometriosis Awareness, PCOS Awareness, and Vulvodynia Support). Table 8 in Appendix W shows which of the organisations responded and promoted the study.

The study adverts consisted of a brief explanation of the study, including the study aim, confidentiality information, the study link, and a contact email (see Appendix X). Women could choose to take part by following the website link to the study. The study questionnaires were all completed online using a University of Southampton-developed online research survey tool, iSurvey.

There is a lack of agreement in the literature regarding the appropriate sample size for exploratory factor analysis (Costello & Osborne, 2005). The appropriate sample size can also depend on the number of items included, with a participant to item ratio of 10:1 recommended in order to reduce sampling error (Fabrigar, MacCallum, Wegener, & Strahan, 1999). According to Tabachnick and Fidell (2001), at least 300 cases would be sufficient for factor analysis. However, a smaller sample size such as 150 participants would also be sufficient under certain conditions e.g., when communalities are high and only a small number of factors, that are defined by at least three strongly loading items, are extracted (Sakaluk & Short, 2016). The final sample size included 969 participants.

Measures

Demographic questionnaire

Participants initially completed a demographic questionnaire that included items that asked about occupation status, relationship/marital status, nationality, and ethnicity. Participants also answered several questions about their pain levels as they were completing the study (see Table 9 in Appendix Y). These questions were used to gauge the participants' current pain levels, to gain insight on the average pain levels over a typical month. Responses were on a 11-point scale ranging from "0" (no pain) to "10" (the worst pain).

The Impact of Female-Chronic Pelvic Pain Questionnaire (IF-CPPQ)

The IF-CPPQ contained 52 items that aimed to assess how the women's CPP impacted on a number of domains, including everyday functioning, mood, social functioning, relationship satisfaction, sexual functioning, and occupational functioning (Appendix Z).

Instructions on the questionnaire were: *“This questionnaire is intended to be used by adult women who experience chronic pelvic pain. The questionnaire aims to assess the impact of chronic pelvic pain on women’s lives in terms of everyday activities (e.g. being able to sit, household tasks, and hobbies), being able to work, socialising, relationships, and sexual relationships. Thinking about the **past month only**, please indicate how much you agree or disagree with the following statements. The questions **concern your chronic pelvic pain**. Please answer each question with respect to your chronic pelvic pain.”*

Items were rated on a five-point scale ranging from “Strongly agree,” “Agree,” “Neither agree nor disagree,” “Disagree,” and “Strongly disagree.” The IF-CPPQ originally contained 72 items. Items were removed and adjusted after gaining feedback from women with CPP in the think aloud study (see Chapter 5).

The Pain Disability Index (PDI) (Ferrero, Young, LaMoreaux, Werth, & Poole, 2001) (Appendix AA)

The Pain Disability Index (PDI) is a seven-item questionnaire and was chosen because it assesses pain-related disability, which is related to the impact of CPP on QOL. The PDI has been shown to be a valid measure (Tait, Chibnall, & Krause, 1990). Responses range from a scale of 0 to 10, whereby a rating of 0 indicates “No disability” and a rating of 10 indicates “Total disability.” It was expected that there would be modest positive correlations between the PDI and the IF-CPPQ.

The World Health Organization Quality of Life (WHOQOL)-BREF (The WHOQOL Group, 1998) (Appendix AA)

This 26-item questionnaire assesses four domains of quality of life: physical health, psychological, social relationships, and the environment. The WHOQOL-BREF has shown good validity and reliability (The WHOQOL Group, 1998). The WHOQOL-BREF was included because it is a generic measure of QOL and it was expected to have moderate positive correlations with the IF-CPPQ.

The Hospital Anxiety Depression Scale (HADS) (Zigmond & Snaith, 1983) (Appendix AA)

The HADS is a 14-item questionnaire that assesses anxiety and depression. The HADS has been previously validated (Bjelland, Dahl, Haug, & Neckelmann, 2002). This questionnaire was included because it was designed for patients in non-psychiatric hospital clinics and research has shown anxiety and depression to mediate the impact of CPP (ter Kuile et al., 2010b). The HADS anxiety and depression scales were predicted to have modest positive correlations with the IF-CPPQ.

The Dyadic Sexual Communication Scale (DSC) (Catania, 2011) (Appendix AA)

This 13-item questionnaire assesses participants' perceptions of the communication process of sexual matters with their partners. This scale has shown good reliability and validity (Catania, 2011). Items are rated on a six-point scale ranging from "Disagree strongly" to "Agree strongly." The DSC was included because the IF-CPPQ contains items that assess sexual and relationship functioning. It was predicted that the DSC would be negatively correlated with the sexual and relationship functioning items on the IF-CPPQ.

The Female Sexual Distress Scale-Revised (FSD-R) (Derogatis, Pyke, McCormack, Hunter, & Harding, 2011) (Appendix AA)

This 13-item questionnaire assesses sex-related personal distress in women. Items are rated on a five-point scale from "Never," "Rarely," "Occasionally," "Frequently," and "Always." This questionnaire has been shown to be valid and reliable (Derogatis et al., 2011). It was predicted that scores on the FSD-R would have strong positive correlations with the sexual functioning items on the IF-CPPQ.

The Social Desirability Response Set (SDRS)-5 (Hays, Hayashi, & Stewart, 1989) (Appendix AA)

This five-item questionnaire was included to assess the degree to which responses were influenced by social desirability. The SDRS-5 has been shown to have good reliability and validity (Hays et al., 1989).

Procedure

To participate, women were required to follow the link to the online study where they would have been presented with a study information and consent sheet (Appendix BB). The information sheet also included the primary researcher's email as well as the supervisors' emails in case the women wanted to ask any further questions. If a woman was happy to participate, she was required to click a check box to indicate she had read the information and agreed to take part. Participants would then be directed to the study questionnaires, which took on average 24.1 minutes to complete (range: 7.3 to 904.8 minutes). After completing the questionnaires, the participants would be directed to a debrief page with links to additional support if needed (Appendix CC).

Ethical issues

The study procedure was approved by the University of Southampton's Psychology ethics committee. As the questionnaire included sensitive topics, such as sexuality issues, it was acknowledged that the participants might feel uncomfortable and experience some negative emotions. To minimise this, the information sheet made it clear to women the kinds of questions that would be asked. Potential participants were also informed that all their responses would be anonymous and that they could withdraw from the study at any point without giving a reason. In addition, participants were provided with a list of helpful resources if they required further support (Pain UK, Pelvic Pain Support Network, Women's Health Concern, Vulvar Pain Society, and Endometriosis UK).

Data protection and anonymity

The study complied with the Data Protection policy of the University of Southampton and the Data Protection Act (1998). Participants were not required to provide their names or any other identifiable information on the questionnaire. Instead, participants' responses were automatically saved on a secure database and allocated a participant ID number.

Data Analysis

Principal axis factor analysis (PAF) was used to assess the factor structure of the IF-CPPQ and to test whether the scales were valid measures of hypothesised factors. The

protocol/guides outlined in Fabrigar et al. (1999), Costello and Osborne (2005), and Pett et al. (2003) were followed. PAF was used to examine the common variance and eliminate error variance within the factor structure of the IF-CPPQ. Oblimin rotation was used as the rotation method to allow for correlations among the subscales (Pett et al., 2003). Criteria for an acceptable factor solution included the following (Pett et al., 2003):

- (1) Factors must have an eigenvalue greater than one.
- (2) Items were excluded if they had a loading of less than 0.3 on factors.
- (3) Items were excluded if they had very low correlations with other items ($r < .3$).
- (4) Items were excluded if they correlated very highly with other items ($r > 0.8$).
- (5) Items were excluded if they had high loading (> 0.3) on multiple factors.
- (6) Items were excluded if they loaded on a factor but were markedly different to other items within the same factor (e.g., a work related item that loaded onto a Sexual Functioning factor would be removed).

Although these criteria were used as a guideline, it was also important that the final solution made theoretical and clinical sense. To achieve this, several solutions were examined before deciding on the final solution.

Internal consistency testing was assessed using Cronbach's alpha, which is expressed as a number between zero and one. The closer the Cronbach's alpha is to one, the higher the internal consistency. As a rule of thumb, alpha values $> .9$ are "Excellent", $> .8$ are "Good", $> .7$ are "Acceptable", $> .6$ are "Questionable", $> .5$ are "Poor", and $< .5$ are "Unacceptable" (Gliem & Gliem, 2003). Convergent validity was assessed using Pearson correlations between factor scores of the IF-CPPQ and the scores on the other questionnaires.

The consistency and model fit of the resulting factor structure was assessed using confirmatory factor analysis (CFA). Maximum likelihood estimation was used as the method of analysis. To determine how well the hypothesised factor model fit the data, three fit indices were used: the X^2 test, the Comparative Fit Index (CFI), and the root mean square error of approximation (RMSEA). The X^2 examines model fit by comparing the estimated correlation matrix under the model with the sample correlation matrix (Kline, 2011). Good model fit is indicated by a small nonsignificant X^2 value, which reflects little discrepancy between the observed and hypothesised model (Kline, 2011). The CFI is an incremental fit index and compares the hypothesised model to a worst fitting or "null" model (Kline, 2011).

A value greater or equal to 0.95 has been suggested to reflect acceptable fit (Hu & Bentler, 1999). The RMSEA is considered to be a “badness-of-fit” index whereby a value of zero indicates the best fit (Kline, 2011). It reflects how close the model fit approximates a reasonably fitted model with good model fit with values <0.05 (Browne & Cudeck, 1993). The data was split in half. One half of the data was analysed using EFA to develop the hypothesised model or factor structure of the IF-CPPQ. The second half was analysed using CFA to confirm the hypothesised model and assess its consistency. Pearson correlations between the IF-CPPQ and the validated questionnaires were conducted on the full data set.

Results

Demographic information

Out of the 969, a total of 815 (84.12%) participants completed all items across all of the questionnaires. The data from the pain related questions are summarised in Table 9 (Appendix Y) for both the EFA and CFA groups and the total sample. Table 10 (Appendix DD) shows the demographic characteristics for the participants from the EFA and CFA groups as well as the total sample.

Exploratory factor analysis (EFA)

PAF was conducted on the 52 items with oblimen rotations. To ensure the results were reliable, data analysis was repeated and resulted in three different factor model solutions. Model 1 was achieved after 13 iterations, model 2 was achieved after 15, and model 3 was achieved after 11 iterations (see Appendix EE for a step by step summary through the decision making process for each model). The Kaiser-Meyer-Olkin (KMO) measure verified the sampling adequacy for the analyses: model 1, $KMO = .89$; model 2, $KMO = .87$; model 3, $KMO = .89$. Bartlett’s test of sphericity was significant in all three models, $p < .001$, which indicates that the correlation matrix was significantly different from an identity matrix (i.e., that there are no relationships among the items). All three models consisted of five factors (or subscales), all with good internal consistency as measured by Cronbach’s alpha. Models 1 and 3 were very similar and consisted of almost identical factors. Both included the following factors: Psychological Impact, Sexual Impact, Relationship Impact, Occupational Impact, and Emotional Impact. They differed in their total number of

items (model 1 had 25 items and model 3 had 27 items). There were also differences in the item factor loadings particularly with the “Psychological Impact,” “Relationship Impact,” and the “Emotional Impact” factors (See Tables 10, 11, and 12 in Appendices EE, FF, GG respectively). The first four factors in model 2 were the same as the other two models. The fifth factor in model 2 differed and consisted of items reflecting everyday functioning.

Although all three models had good factor structures, model 3 was chosen as the superior model. This is because its factor structure was more stable, which was demonstrated by the fact that models 1 and 3 consisted of the same factors. The factor solution for model 3 also accounted for a higher proportion of the variance compared with the other two models. Furthermore, the item loadings in Model 3 made better theoretical sense compared with Model 1 even though the overall factors were the same. For example, item 43 (“I felt that I have not been “heard” or listened to by people close to me when I have talked about my pain”) loaded onto the Relationship Impact factor in Model 1, which seemed out of place because the other items concerned issues relating specifically to one’s partner. In Model 3, this item was replaced with item 33 (“I felt closer to my partner because of the pain”).

Table 13 (Appendix HH) provides a summary of the results for Model 3, which contained 27 items that in combination explained 62.75% of the variance. Table 12 also provides the internal consistency reliability results for each subscale as measured using Cronbach’s alpha. All the subscales had high reliabilities. The Cronbach’s alpha of the IF-CPPQ overall was 0.64. Tables showing summaries of Models 1 and 2 are provided in Appendix FF and GG, respectively.

Confirmatory factor analysis

Results of the CFA assessing the fit of Model 3 (a 5-factor model) are presented, followed by a description of modifications made to improve model fit. CFA was also used to assess the fit of model 2 as a comparison to model 3. This was done to help determine which of the two models were a better fit of the data. Because model 3 was chosen as superior to model 1 as previously discussed, CFA was not conducted on model 1. A 1-factor model whereby all the items loaded onto one factor was also assessed to test the assumption of unidimensionality. The results of the fit indices for all three models, including the unidimensional model, are summarised in Table 13 (Appendix HH).

The results in the top half of Table 13 are based on Models 2 and 3 as indicated by the findings from the EFA. Both models resulted in a high Chi-square that was significant at $p <$

.001, which is indicative of poor model fit. However, the Chi-square is known to be very sensitive to sample size and can be failed when conducted on large samples even with very slight differences between the observed and predicted covariances (Blunch, 2013; Kline, 2011). This issue is overcome by the fit indices CFI and RMSEA, which indicated good model fit for both models 2 and 3. The Chi-square, CFI, and RMSEA all showed an improvement of model fit when error covariances were estimated. Seven covariances between error variables in model 2 were estimated and 14 for model 3. Tables showing the regression weights for models 2 and 3 are provided in Appendix JJ and KK, respectively. All of the regression weights in both models were statistically significant at the $p < 0.001$ level. However, item 42 (I felt anxious about experiencing pain during sexual activity in future relationships) was found to be the only item in both models with a p-value equal to 0.001. Although this was statistically significant, this was the greatest p-value compared with the rest of the items. When item 42 was removed, model fit was improved in both models as indicated by a reduction in the Chi-square and RMSEA and increases in the CFI. These data are shown in the bottom half of Table 13.

The results of the Chi-square indicated that model 2 was a better fit of the data than model 3. However, the fit indices indicated both models had good fit. The CFI was only slightly higher for model 3 suggesting better model fit. These findings made it difficult to decide which of the two was a superior model. Because the models mainly differed in their fifth factor (Psychological Impact in model 3 vs General Functioning in model 2), the characteristics of the distributions of the data for these factors were investigated. Figure 4 (Appendix LL) shows histograms that illustrate the distributions of data for the Psychological Impact subscale from model 3 and the General Functioning subscale from model 2.

As shown in Figure 4 (Appendix LL), both histograms show negative skewness. This means the distribution of scores were more at the higher end of the scales. The General Functioning subscale was more negatively skewed with a skewness statistic of -1.14 (SE, 0.08) compared with -0.66 (SE, 0.08) for the Psychological Impact subscale. Kurtosis was 1.64 (SE, 0.16) for the General Functioning subscale and 0.00 (SE, 0.16) for the Psychological Impact subscale. Although it was expected that the data for these subscales would be negatively skewed, the results suggest that more women will likely score higher on the General Functioning subscale compared with the Psychological Impact subscale. This is because based on findings from the qualitative study discussed in Chapter 4, more women with CPP (with varying degrees of severity) are likely to relate to the items from the General Functioning subscale. Such items include “I found it difficult to sit because of the pain,” and

“The pain has stopped me from doing everyday activities that I would normally do (e.g., household jobs).” However, items from the Psychological Impact subscale reflect more severe psychological consequences of the pain. It is therefore expected that women who are more severely affected by their pain are more likely to endorse these items. Examples of items from the Psychological Impact subscale include “I felt that my pain has taken away my life,” and “I have had thoughts about ending my life because of the pain.” In addition, there is more variability in scores for the Psychological Impact subscale compared with the General Functioning Subscale. This suggests that the Psychological Impact subscale is likely to be better at discriminating between those that score high and those that score low on this subscale compared with the General Functioning subscales. Therefore, the Psychological Impact subscale is likely to provide more information on the severity of the impact of CPP. Taken together, model 3 (with the removal of item 42) was chosen as the final solution for the IF-CPP. Table 17 (Appendix MM) shows both the standardised and unstandardised regression weights of the items in model 3 without item 42. Table 18 (Appendix NN) shows the standardised and unstandardised regression weights of the items in model 2 without item 42. Table 19 (Appendix OO) shows the correlations between factors in model 3.

Pearson correlations between the IF-CPPQ and validated measures

Before the Pearson correlations were calculated, the internal consistency of the other questionnaires administered was assessed using Cronbach’s alpha. All of the questionnaires had good internal consistency (see Table 20 in Appendix PP). Pearson correlations were conducted between the IF-CPPQ subscales and the other validated questionnaires (see Table 21 in Appendix QQ). Pearson correlations were also conducted between the total IF-CPPQ total score and the WHOQOL-Bref overall quality of life question, the WHOQOL-Bref overall quality of health question, and the PDI. All of the correlations were significant at the $p < .001$ level in the expected direction. Pearson correlations were also used to compare social desirability scores from the SDSR-5 to the IF-CPPQ subscale scores and total score. The majority of the correlation coefficients were non-significant. However, the SDSR-5 was significantly positively correlated with the Psychological Impact subscale at $p < 0.001$. The SDSR-5 was used to assess social desirability in the response. Although the results overall indicated the responses to the IF-CPPQ were not greatly influenced by social desirability, there was indication that responses to the Psychological Impact may have been influenced by social desirability as indicated by the significant positive correlation with the Social

Desirability Response Set (SDRS)-5. Despite the significant finding, the positive correlation between the SDRS-5 and the Psychological Impact subscale was low at 0.123 (See Table 20).

Discussion

The IF-CPPQ was developed to assess the impact of CPP on women's lives. The items were generated based on qualitative interviews and have been piloted in think aloud interviews, in both instances with women experiencing CPP (see Chapters 4 and 5). The IF-CPPQ assesses the impact of CPP on several facets of women's lives, including emotional wellbeing, occupational wellbeing, sexual functioning, and relationship functioning. The purpose of the current study was to assess the psychometric properties of the IF-CPPQ and evaluate whether it is a valid and reliable measure.

Before data analysis, the IF-CPPQ had 52 items; this was reduced to 26 items. EFA was conducted on the initial 52 items of the IF-CPPQ and the final solution contained five factors (or subscales) all with good internal consistency that ranged between .72-.91. The subscales included the following: Psychological Impact, Sexual Impact, Relationship Impact, Occupational Impact, and Emotional Impact.

The consistency and model fit of the chosen five-factor solution was assessed using CFA. Although the fit indices CFI and RMSEA indicated good model fit, the five-factor solution failed the Chi-square test, which is indicative of poor model fit. However, the Chi-square test is known to be very sensitive to sample size and tends to be failed when conducted on large samples even with very slight differences between the observed and predicted covariances (Blunch, 2013; Kline, 2011). The factor solution was further improved with the removal of item 42, which resulted in a five-factor solution made up of 26 items (see Appendix RR for the final questionnaire).

Finally, Pearson correlations between the IF-CPPQ subscales and additional questionnaires that measure related constructs were all in the expected direction. For instance, significant positive correlations were found between the Emotional Impact subscale and the HADS depression and anxiety subscales. These correlations were expected because higher scores on the Emotional Impact subscale and the HADS scales indicate greater emotional distress. In addition, a significant negative correlation was found between the Relationship Impact subscale and the DSC. This was expected because a high score on the Relationship Impact subscale and a low score on the DSC indicates poorer relationship satisfaction. These

findings indicate that the IF-CPPQ has good convergent and discriminant validity. Moreover, for the most part responses on the IF-CPPQ were not significantly influenced by social desirability. However, responses on the Psychological Impact subscale were very likely influenced by social desirability. This may have been because the items on this subscale tap into a more severe psychological impact of the pain, which can be difficult to answer compared with items on the other subscales. For example, “I felt that my pain has taken away my life”, and “I have had thoughts about ending my life because of the pain” are questions that ask about suicidal ideation and the global impact of the pain. Such matters might be difficult to talk about and therefore lead to the possibility of responding in a socially desirable way. Nonetheless, the significant correlation was quite low, albeit significant.

Chapter 2 discussed quality criteria for measurement properties recommended by Terwee et al. (2007). A number of quality measurement properties have been assessed and achieved. Content validity was achieved through the qualitative study in Chapter 4 and the think aloud study in Chapter 5. This is because these studies ensured the items of the IF-CPPQ were representative of the different factors related to the impact of CPP. As discussed, internal consistency was assessed and achieved using Cronbach’s alpha in the current study. Concurrent and construct (convergent and discriminant) validity were assessed and achieved by correlating the IF-CPPQ total and subscale scores with other validated measures that assessed related constructs. Although most of the quality criteria had been assessed and achieved, a number of measurement properties were not evaluated. Unfortunately, responsiveness and interpretability of the IF-CPP was not investigated. Assessing the responsiveness and interpretability of the IF-CPP is important because it would determine whether the questionnaire is able to detect clinically meaningful changes on impact over time. In addition, the scores on the questionnaire could be interpreted and reflect a meaningful severity of impact.

The remaining measurement properties that were not assessed included predictive validity, reproducibility, and floor and ceiling effects. However, these properties would be difficult to assess and are less likely to add value to the IF-CPPQ. This is because CPP is a long-term and usually very unpredictable. Therefore, scores on the IF-CPPQ will likely be inconsistent over two time points. Finally, due to the debilitating nature of CPP, many participants will likely score relatively high on the IF-CPPQ indicating ceiling effects. Consequently, a normal distribution is not expected and would be difficult to achieve with this particular sample.

As discussed previously, many studies that have assessed the impact of CPP have used either questionnaires that were developed only for the purpose of the study (Engel et al., 1998; Grace & Zondervan, 2006) or generic standardised measures. Although the majority of the questionnaires used in CPP research have demonstrated good validity, they have shown poorer face validity when used with women with CPP (Neelakantan et al., 2004). Unlike previous questionnaires, the items on the IF-CPPQ are more clearly relevant because of the development process undertaken. This is because input from women with CPP was received at all stages of the development of the IF-CPPQ (see Chapters 4 and 5).

As discussed previously, there are a number of disease-specific questionnaires that have been designed to focus on certain CPP conditions. Although such measures are useful for assessing disease-specific symptoms, especially when women with CPP are diagnosed with certain conditions, they are less helpful when women with CPP do not have a diagnosis or have been diagnosed with multiple conditions. Because the items on the IF-CPPQ are not tied to specific CPP conditions, it can still be used by women who have no formal diagnoses or multiple CPP conditions. Many disease-specific questionnaires focus on the characteristics of pain symptoms (e.g., intensity, duration, pain during sex) and less on the actual impact of the pain (O'Leary et al., 1997; Parsons et al., 2002). The IF-CPPQ differs in that its purpose is to assess the impact of CPP and how much women are affected by their pain. This is also reflected by the IF-CPPQ response options, which allow women to indicate how much they are affected by their pain by specifying how much they agree or disagree with the questions. Instead, other questionnaires such as the EHP-30 use response categories that indicate how often particular events have occurred (e.g., "Never," "Sometimes," and "Always"). The issue with such response options is that they do not indicate how much the participants are impacted by their symptoms, only how often they have occurred over the length of time in question.

Important areas of life that tend not to be adequately evaluated by other questionnaires used to assess CPP include relationship and sexual functioning (Jones et al., 2001; O'Leary et al., 1997; Parsons et al., 2002; Patrick et al., 1998). Such issues are very relevant and important to women with CPP (Butt & Chesla, 2007; Smith et al., 2013; Sutherland, 2012). The IF-CPPQ includes two subscales that assess the impact of CPP on relationships and sexual functioning; items on these subscales were derived from themes identified in a large qualitative study that explored the impact of CPP (see Chapter 4). Regarding sexual functioning, women with CPP report significantly decreased sexual function in comparison to pain-free women, as well as higher levels of pain with intercourse,

sexual avoidance, and sexual dissatisfaction (Smith et al., 2013; ter Kuile et al., 2010b). The impact of CPP on relationships with sexual partners is also important but has been given less attention compared with sexual functioning (Daniels et al., 2009; Giuliani et al., 2016; ter Kuile et al., 2010b). Many women have reported on how their CPP has had a negative impact on their relationships beyond sexual functioning (see Chapter 4). Consequently, it is important to assess the impact of CPP on personal relationships separately from sexual functioning. The IF-CPPQ also contains two subscales that assess the impact of CPP on emotional wellbeing as well as on more severe psychological wellbeing unlike previous CPP questionnaire that were designed to focus diagnosis and screening (Mohedo et al., 2013; van Os-Bossagh et al., 2002).

Strengths and Limitations

The current study had a number of strengths. The IF-CPPQ items were developed based on qualitative interviews with women with a wide variety of CPP conditions (see Chapter 4). The qualitative data provided good insight into the number of ways women with CPP can be affected by their pain. A patient-led approach was used in developing the IF-CPPQ and the items concern how CPP has impacted women's lives from their perspective. The IF-CPPQ considers the emotional and psychological impact of CPP, which have sometimes been overlooked in CPP research (Fenton et al., 2009; Nesbitt-Hawes et al., 2013; Palomba et al., 2006). Psychological distress has been found to be very high in individuals with CPP and is associated with significant functional impairments (Miller-Matero et al., 2016). Therefore, it is important that a measure of CPP assess psychological and emotional consequences of the pain. Feedback on the initial items was also gained from women with CPP in a think-aloud study, which further shaped the IF-CPPQ (see Chapter 5) (Charters, 2003). The think-aloud study ensured the items were comprehensible and provided an opportunity to remove or re-word ambiguous items. Both of these studies were important in ensuring the IF-CPPQ had good content and face validity. Finally, another strength was the large sample size that included women from a number of different countries. The large sample size allowed for both EFA and CFA to be conducted, which provided better support for the overall factor structure of the IF-CPPQ.

Study limitations also need to be acknowledged. The decision making process in EFA has a subjective component. Although criteria were used to help determine an acceptable

factor solution, strictly following the criteria would not have been helpful and some of the decision-making process had to be based on logical sense. There are also limitations with the use of fit indices in CFA. Values of fit statistics only indicate the average or overall fit of a model (Kline, 2011). Therefore, even if some aspects of the model poorly fit the data, the value of fit statistics can still be favourable. In addition, there is little relation between values of fit indices and the degree or type of misspecification i.e., they do not indicate how much the model departs from the data (Kline, 2011). Finally, fit statistics do not indicate whether the results are theoretically meaningful (Kline, 2011).

Thresholds for fit indices that are widely used (Hu & Bentler, 1999) were intended to be used as “rules of thumb” only. However, there is the issue of “fit statistic tunnel vision” whereby researchers become so preoccupied with fit statistics that other information e.g., whether the parameter estimates actually make sense, is overlooked (Kline, 2011). Therefore, as with EFA, it is important for researchers to use interpretation guided by theoretical understanding of their data (Sakaluk & Short, 2016).

The development of the questionnaire did not involve any input from health professionals. Although the focus is on the impact of CPP from the women’s perspective, health practitioners involved in the management and treatment of CPP may have knowledge of additional areas of life that are impacted by the pain and which may have been missed.

A final limitation concerns the sociodemographic characteristics of the sample. Although a good sample size was obtained across a number of different countries, over 90% of the participants were white. It is important for any future studies to try and recruit participants with more diverse backgrounds.

Potential uses of the IF-CPPQ

The IF-CPPQ questionnaire has the potential to be used in a number of ways. First, the IF-CPPQ can potentially be used in treatment studies that aim to improve CPP. It is important to assess the impact of CPP as well as pain severity in treatment studies because this provides a better indication on how much women are affected by their pain. A number of studies have used generic measures to assess improvements in CPP in a range of outcomes including pain, quality of life, and sexual functioning. Examples of such measures include the visual analogue scale, the Short Form-12 (Ware et al., 1996), the Female Sexual Function Index (Rosen et al., 2000), and the Brief Pain Inventory (Cleeland & Ryan, 1994). The IF-

CPPQ can be used as an outcome measure at baseline and to assess improvement in the impact of CPP alongside additional generic measures. Because the IF-CPPQ is not disease-specific, it can be used to assess impact of CPP in women with a variety of conditions, even those with no formal diagnoses. Additionally, the IF-CPPQ can be used to select women into intervention/treatment trials who have been more severely impacted by their CPP. Finally, the IF-CPPQ can potentially aid communication between women with CPP and their practitioners so that women can communicate how their pain is impacting their lives rather than just their pain levels. Although there are a number of suggested uses of the IF-CPPQ, more research is needed to determine its ability to detect clinically meaningful changes in impact of pain after treatment.

Conclusions

This chapter presents the final stage of the development of a new CPP questionnaire, the IF-CPPQ. The results show that the IF-CPPQ is a reliable and valid measure of the impact of CPP. Based on both EFA and CFA, the IF-CPPQ has five subscales, which include the following: Emotional Impact, Sexual Impact, Relationship Impact, Occupational Impact, and Psychological Impact. These factors tap into important experiences with CPP and the development of the items were informed by qualitative interviews with women with CPP. The IF-CPPQ has the potential for multiple uses within research and clinical practice but further research is needed to determine its ability to detect clinically meaningful changes.

Reflexive comments

Overall, I think the development of the IF-CPPQ has gone well and smoother than expected. I was initially concerned that not enough participants were going to participate in my study. To my relief, I ended up with a much higher sample than expected, which meant I was able to conduct both EFA and CFA.

Before conducting my data analysis, I had to do quite a lot of reading to prepare. Surprisingly, I found the literature on factor analysis very interesting and found myself quite immersed in the literature. I had no idea there was so much literature debating the treatment of Likert scales as interval vs ordinal data. Reading also gave me the opportunity to revise and go back to basics, which I found very helpful.

Conducting the data analysis took a bit longer than I had anticipated. This is because I repeated the EFA a few times, resulting in three different solutions. At first all three models made sense and it was difficult to select one. After looking at the models in more detail and taking time to think it through, I was confident that model 3 was the superior model and that this would be reflected in the subsequent analyses. Because the IF-CPPQ has been shaped by two qualitative studies beforehand (Chapters 4 and 5), it is all the more relevant to women with CPP. Developing the IF-CPPQ has been a rewarding experience and I hope it will be used in future research and clinical settings.

Chapter 7: General Discussion

Chapter overview

This final chapter will provide a recap of the main research aims and will summarise the main findings of the thesis. This is followed by a discussion of how the findings fit with current research. The methodological strengths and weaknesses of the research overall will be highlighted as well as the implications of the findings for further research, policy, and practice. The chapter will end with some concluding statements.

Reminder of main thesis aims

The aim of the current thesis was to explore the experiences of women with CPP and provide a thorough review of research examining different treatments and interventions for women experiencing sexual pain. Based on these findings, the objective was to develop a new measure that assesses the impact of CPP on women's lives. This includes how pain impacts everyday tasks, work, social functioning, relationship satisfaction, sexual functioning, and emotional wellbeing. Specifically, the following research questions were examined to address these aims: (1) Which treatments for female sexual pain have been evaluated in clinical studies? (2) What is the effectiveness of these treatments? (3) When follow-ups are carried out, are improvements in sexual functioning, satisfaction, or pain maintained? These questions were addressed in a systematic review (Chapter 3). (4) How do women with CPP cope with their pain and how do they perceive the impact of their pain on their life in terms of work, socialising, hobbies, exercise, and personal relationships? (5) Which areas of life affected by the pain do women with CPP consider important? This was addressed using qualitative methods (Chapter 4). (6) Does the new CPP questionnaire have good face validity, convergent validity, and reliability? This has been addressed using both qualitative and quantitative methods (Chapter 5 and 6).

Summary of main findings

Study 1: Systematic review (Chapter 3)

The systematic review of 65 studies provided a good overview of the different treatment modalities for female sexual pain problems. These were divided into the following categories of treatments: medical treatments; surgical treatments; physical therapies; psychological therapies; and miscellaneous and combined treatments. Medical treatments included topical medications, systemic medications, and injections. Botox, nerve blocks, amitriptyline, and lidocaine have generally been found to lead to improvements in, but not complete relief of, pain; side effects associated with these treatments are quite common.

Surgical procedures that were identified included vestibulectomies, modified vestibulectomies, and laparoscopic surgeries. The surgical procedures overall have demonstrated high success rates, although there has been variability in the proportion of women who experience complete relief of pain after surgery; less invasive treatments should be considered first. The outcome measures assessed in the surgical treatment studies were often limited to pain and other physical indices, making it unclear whether the procedures were effective in improving other aspects of women's lives, such as sexual functioning and satisfaction.

Physical therapies identified included desensitisation with dilators, electrical stimulation, electromyographic (EMG) biofeedback, and combined physical therapy programs. Psychological therapies included CBT approaches, the use of surrogate partners, and educational seminars. Physical therapies and psychological therapies have been shown to be promising treatments, supporting a biopsychosocial approach to sexual pain disorders. Although most of the interventions described have been reported as effective, many women still experience pain. A multidisciplinary team with active patient involvement may be needed to optimize treatment outcome.

Study 2: Qualitative study (Chapter 4)

Among the 25 female participants recruited for the qualitative study, CPP had had an impact on virtually every aspect of their lives, including their ability to work, socialise, engage in hobbies, and exercise. One of the major effects of CPP was on sexual functioning. In some instances, it was not possible for women to have sexual intercourse because of the pain, which caused tension in relationships. The CPP experienced by many of the women in

the qualitative study was frequently “normalised” by either the women themselves or by medical professionals, and this likely contributed to the frequent delays in diagnoses. Another major impact of the women’s CPP was on emotional wellbeing and general day-to-day functioning. Some women no longer felt like the same person because they essentially had to adapt to a new life with CPP. The profound impact of the CPP on the women’s lives often led to strong negative emotional consequences, including anger, frustration, and depression. It is therefore important that health professionals acknowledge the diverse impact of CPP on the women and how it may affect them emotionally and psychologically. Like the systematic review, the findings from the qualitative study support a multidisciplinary treatment approach that aims to improve quality of life. The varied impact of CPP the qualitative study revealed demonstrated the need to assess different aspects of women’s lives, and not simply their pain levels.

Study 3 and 4: Think-aloud study and questionnaire development study (Chapters 5 and 6)

The findings from Chapter 4 informed the development of the new CPP questionnaire – The Impact of Female Chronic Pelvic Pain Questionnaire (IF-CPPQ), initially comprising 72 items. Items were developed based on data from the qualitative study (Chapter 4). The development of the items was also based on previous literature on the impact of CPP and relevant disease-specific measures (Ballard et al., 2006; Grace & MacBride-Stewart, 2007; Jones et al., 2004a; Jones et al., 2001; Price et al., 2006; Rogers et al., 2013). The feedback from the participants during the think-aloud study (Chapter 5) was overall quite positive and the majority felt that the IF-CPPQ adequately assessed the impact of CPP. The majority also found the questions to be clear, easy to understand, and thought the questionnaire would be a useful way of communicating issues to healthcare professionals. Many participants felt that that questionnaire was very comprehensive and covered most of the ways that they had been affected by their pain, which led to them feeling “validated” by the questionnaire. Despite the positive feedback overall, some participants had suggestions for improvement. The feedback from the think-aloud study resulted in reducing the 72 items to 52 items mainly because of overlap between items and some items not being that relevant to the impact of CPP. The findings from the think-aloud study overall suggested that the IF-CPPQ has good content and face validity.

The final quantitative study assessed the validity, reliability and psychometric properties of the IF-CPPQ. After conducting EFA, the items on the IF-CPPQ were reduced further to 26 items that comprised the following five subscales: Psychological Impact, Sexual Impact, Relationship Impact, Occupational Impact, and Emotional Impact. All the subscales had good internal consistency. The findings of the CFA provided further evidence of good model fit. Pearson correlations between the IF-CPPQ subscales and additional questionnaires that measure related constructs, e.g. mood, were all in the expected direction, indicating that the IF-CPPQ has good convergent and discriminant validity.

Contributions of the current thesis

Theoretical implications

CPP and sexual functioning and satisfaction

The systematic review (Chapter 3) and the qualitative study (Chapter 4) have highlighted the impact of CPP conditions on sexual functioning and satisfaction in addition to sexual pain. Many previous studies have focussed on sexual pain and the ability to have penetrative sexual intercourse (PSI), with the assumption that this is associated with sexual satisfaction and functioning (Baggish, 2012; Bornstein et al., 2010; Farajun et al., 2012; Fenton et al., 2009; Murina et al., 2013). However, self-report measures and objective pain ratings (e.g., cotton-swab test, vestibular pressure-pain threshold measurements) are not associated with sexual functioning and satisfaction (Aerts, Bergeron, Pukall, & Khalifé, 2016). In addition, CPP does not always lead to a reduction in sexual activity (Montenegro et al., 2010). This suggests that sexual functioning in women with CPP is much more complex and additional factors need consideration alongside pain. The qualitative study provided an opportunity for women with CPP to expand on their experiences of pain during sexual intercourse. Not only was intercourse painful but most of the women expressed how they no longer had any desire to engage in sexual intercourse, nor did they find it enjoyable. This suggests that sexual desire and enjoyment are also important when assessing sexual functioning and may play a mediating role between sexual pain and sexual functioning.

Many of the studies discussed in the systematic review focused on ability to have penetrative sexual intercourse, rather than sexual activity more generally (e.g., non-

penetrative sexual activity) as a measure of sexual functioning (Har-Toov et al., 2001; Schnyder et al., 1998; Steinberg et al., 2005; Ventolini et al., 2009; Zolnoun et al., 2003). The women recruited in the qualitative study also expressed a greater regard for penetrative sex than for non-penetrative sexual activities. A number of the women felt inadequate for not being able to engage in PSI and felt dissatisfied with non-penetrative sexual activities. Some also stated they would avoid non-penetrative sexual activities because of the fear that this would lead to intercourse. In contrast, some women felt that it was important to engage in some sexual activity such as foreplay to avoid the threat of their partner satisfying their sexual needs elsewhere. Moreover, a number of women reported that if they did not engage in sexual intercourse, they were not fulfilling a role they perceived was expected of them as women/wives. These findings highlight the complexities around women with CPP and sexual relationships/activity and illustrate how women with CPP can differ in their reasons for engaging in sexual activity, which can have implications for sexual satisfaction. This also highlights why only measuring sexual frequency and whether sexual intercourse has occurred may be insufficient.

The widespread impact of CPP and a move away from focussing on pain and medical treatments

Another important implication of the current thesis is that it highlights the wide-ranging impact of CPP on women's lives. Findings from the systematic review (Chapter 3) and qualitative study (Chapter 4) suggest moving away from a biomedical view of CPP to a more holistic perspective. The findings support a biopsychosocial approach to treating sexual problems experienced by women with CPP and suggests benefits can be achieved from a number of treatment modalities to relieve pain and improve sexual function and psychological adjustment (Bergeron et al., 2001; Bergeron et al., 2008; Danielsson et al., 2006). These include physical therapies (e.g., dilators, electrical stimulations, and EMG biofeedback) and psychological therapies, particularly CBT.

The qualitative study also demonstrated that CPP can have a negative impact on almost every aspect of women's lives, including their ability to work, socialise, engage in hobbies, and exercise. Descriptions of just the pain itself took up smaller portions of the interviews. It is important that health professionals acknowledge the diverse impact of CPP on the women and how it may affect women emotionally and psychologically. Additional

findings from the qualitative study included the difficulties the women experienced being able to communicate their pain to their health professionals as well as to people close to them. The development of the IF-CPPQ acknowledges the wide-ranging impact of CPP and includes items that focus on the impact of the pain rather than on characteristics of the pain. Because of this, the measure could potentially be used to help health professionals assess how women with CPP are affected by their pain.

Previous research has mostly used either pain measures or generic quality of life measures to assess CPP and the effectiveness of interventions or treatments (Abbott et al., 2006; Bergeron et al., 2001; Bergeron et al., 2008; Corsini-Munt et al., 2014; Curran et al., 2010; Fenton et al., 2009; Heyman et al., 2006; Nesbitt-Hawes et al., 2013). The IF-CPPQ measures issues that women with CPP consider important to them and has demonstrated good validity and reliability (Chapter 6). It can therefore potentially be used alongside other pain measures in therapy/treatment outcome studies. This can be more valuable than just measuring the extent of the pain. Women with different CPP conditions, including those without a formal diagnosis, can also complete the IF-CPPQ. In addition, the IF-CPPQ can help aid the selection of participants in treatment trials. For instance, it may be that researchers would like to enrol only women who are greatly affected by their pain and score high on the IF-CPPQ or women who are interested in reducing the impact of CPP in one area e.g., sexual impact. Finally, the IF-CPPQ can potentially be used to aid communication between patients and health practitioners. The treatment and management of CPP should use a multidisciplinary approach and not just focus on the pain alone (Rhodin, 2013). The IF-CPPQ can potentially allow patients to communicate the different ways their pain is affecting their lives. This may also inform whether referral to additional health practitioners or therapists is required.

The impact of CPP on couples and not just the individual

Findings from the current thesis acknowledge and inform on the impact of CPP on couples both in sexual and in non-sexual dimensions (Chapter 4). Not surprisingly, the participants discussed more negative than positive consequences of their CPP. Some women described how their partners would express feelings of frustration about there not being anything they could do to eliminate the pain. This was reported by the participants to put quite a lot of strain on the relationship and cause arguments. Other participants felt that their

partners had become quite dismissive over time and were not always sympathetic towards their pain. Being in a relationship added pressure on some women to be “normal” and be able to engage in different activities that are difficult with the pain e.g., going out.

Findings from the qualitative study also reflect the importance of communication between partners. The women frequently reported experiencing difficulties explaining their pain and getting their partner to understand its impact. Partners were reported to underestimate the intensity and frequency of the women’s CPP and in some cases not realise the unpredictability and inconsistency of the pain. For many women, not being able to discuss their pain with their partners created difficulties in the relationship. Some women reported being too anxious or scared to talk to their partners out of fear of receiving an undesirable response. The findings suggest improved communication between couples may possibly lead to less impact of CPP on women’s relationships.

There is research that suggests that interpersonal factors can contribute to developing and maintaining chronic pain conditions (Leonard, Cano, & Johansen, 2006). Pain behaviours, such as verbalisations, communicate pain to significant others who may then react in a reinforcing or punishing manner (Rosen et al., 2014). Partner responses to pain may either be solicitous, negative, or facilitative (Rosen et al., 2014). Solicitous responses may include stopping activities that lead to pain altogether; negative responses include the partner expressing anger; and facilitative responses include the partner expressing happiness or support that a partner with CPP has engaged in a difficult activity (e.g. sexual intercourse, exercise, household tasks). Solicitous and negative responses promote avoidance of potentially pain-inducing behaviours, whereas facilitative responses are thought to encourage adaptive, coping behaviours (Rosen et al., 2014). Such partner responses to pain behaviours can be conceptualised under operant learning theory (Fordyce, 1976). There has been support for the operant model in chronic pain research, which has shown facilitative and less solicitous and negative partner responses are associated with lower pain and disability (Raichle, Romano, & Jensen, 2011; Rosen, Bergeron, Glowacka, Delisle, & Baxter, 2012; Rosen et al., 2014). Some women that participated in the qualitative study reported becoming more open with their partners since the onset of their pain and also reported that their relationships had become much more affectionate. In such relationships, the partners were described as very supportive and the women discussed how they were able to manage their CPP better. This provides some indication of the importance of relationship dynamics in the treatment of CPP in women. Because the focus of the thesis was to explore the impact of CPP on women, rather than on dyads, no robust conclusions on this topic can be drawn.

Clinical implications

Treatments

Many of the findings from the current thesis have treatment and therapeutic implications. The problems as a consequence of CPP experienced by women are very multidimensional and include negative effects on their relationships, sexual functioning, social functioning, general functioning, and occupational functioning (Chapter 4). It is important that health professionals acknowledge the diverse impact of CPP on women and how it may affect them emotionally and psychologically. Because of the multifaceted nature of CPP, treatment should not only be directed at eliminating pain but should also attempt to improve the quality of life of women with CPP.

Regarding women who experience sexual pain, a move away from the focus on intercourse as a goal of treatment is also needed. In clinical settings, the importance that women and their partners (and sometimes clinicians) place on intercourse needs to be challenged. Couples can be guided and counselled to find mutually pleasurable sexual activities that may or may not include penetration. The development and evaluation of integrated treatment programs pose unique challenges, but these programs may provide the best means to target the multidimensional features of sexual pain disorders (Bergeron et al., 2010).

If women are in a relationship, the findings from the thesis suggest it would be beneficial for therapeutic approaches to involve the partner. Such therapeutic approaches should focus on strengthening communication between the couple. Improving communication can potentially help couples manage CPP more effectively and reduce its impact. The couple can also be educated about CPP together as a unit, so that they both have an understanding on the pain and its implications. In addition to CPP, the couple can also be made aware of the impact of interpersonal factors in the development and maintenance of chronic pain conditions (Leonard et al., 2006). This can include the impact of solicitous, negative, or facilitative partner responses (Rosen et al., 2014).

Based on the findings of the current thesis, it is advised that a comprehensive assessment is needed to understand the pain experience of women with CPP (Goldstein et al., 2016). It is likely best to progress from less invasive to more invasive treatment, and it is expected that several treatment options may need pursuing (Goldstein et al., 2016). Due to

the chronicity of CPP and its impact on psychological and emotional wellbeing, psychological treatments should be the first-line approach (e.g., cognitive behavioural approaches, and mindfulness) as well as multidisciplinary team/support.

The IF-CPPQ can potentially be used in intervention studies that aim to improve CPP, for example, as an outcome measure at baseline and to assess improvement in the impact of CPP alongside additional generic measures. Because the IF-CPPQ is not disease-specific, it can assess CPP in women with a variety of conditions, including women with no formal diagnoses. Furthermore, the IF-CPPQ can be used to select women into intervention or treatment trials who have been severely impacted by their CPP. Finally, the IF-CPPQ can potentially aid communication between women with CPP and their health practitioners and increase practitioners' understanding of how pain is impacting their patients' lives.

Challenges in this area of research

A major challenge in this area of research concerns the lack of consensus around the definition of CPP, which reduces the ability for researchers to investigate causes for the pain and improve treatment options (Williams, Hartmann, & Steege, 2004). Important aspects of a working definition of CPP such as duration and location of the pain are not consistently defined. For instance, some researchers require a duration of at least three months of CPP, while others require at least six months of pain (Abercrombie & Learman, 2012; Latthe et al., 2006a; Rhodin, 2013; Tu, Holt, Gonzales, & Fitzgerald, 2008; Weijenborg, Ter Kuile, & Stones, 2009). In addition, some but not all researchers define CPP to include only noncyclic pain and exclude participants whose pain only occurred during menstruation or sexual intercourse (Montenegro et al., 2010; Price et al., 2006). Some studies included only women who experience constant pain rather than intermittent pain (Brown, Ling, Wan, & Pilla, 2002), while others also include women with intermittent pain (Warwick et al., 2004). A minority of studies have included cyclic pain (Latthe et al., 2006a). Several studies did not consider or exclude confirmed CPP conditions such as endometriosis and IBS (Brown et al., 2002; Heyman et al., 2006; Stones, Bradbury, & Anderson, 2001). Such conditions can be the cause of the pain and, as shown in the current thesis (Chapters 4, 5, and 6), are very common in women with CPP. It is vital to have a consistent definition of CPP to improve research in this field. A working definition of CPP will also help improve consistency and comparisons across studies, which could potentially improve current knowledge understanding of the pain.

Methodological strengths and limitations of the thesis

The systematic review of the literature conducted was a strength of the current thesis (Chapter 3). It enabled the identification and synthesis of a large number of research studies investigating treatments for female sexual pain problems. The systematic approach used resulted in a comprehensive account of the different treatments that have been used and which have been most effective for women experiencing sexual pain. In the context of CPP, this is particularly important given that a very large proportion of women experience pain with sexual activity.

Another strength of the thesis was the adoption of both qualitative and quantitative methods. The qualitative study (Chapter 4) enabled in-depth information on the impact of CPP on women. This resulted in a very rich dataset and a deep understanding of women's experiences of CPP. The findings of the qualitative study were then used to inform the development of the preliminary versions of the IF-CPPQ items. The first version of the IF-CPPQ was then piloted in a think-aloud study, which provided useful data on what women with CPP thought about the measure. The findings from the think-aloud study resulted in significant changes to the IF-CPPQ items (Chapter 5). The psychometric properties of the IF-CPPQ were then assessed in a large quantitative study (Chapter 6).

The samples recruited in the thesis also had a number of strengths. The qualitative (Chapter 4), think-aloud (Chapter 5), and quantitative (Chapter 6) studies included heterogeneous samples of women with CPP. They included women that have been diagnosed with different CPP conditions such as endometriosis, pelvic adhesions, interstitial cystitis, and also women with no formal diagnoses. The sample of women included in the quantitative study (Chapter 6) was substantial. Because the sample size was large, it meant that both exploratory and confirmatory factor analyses could be conducted, which provided additional support for the psychometric properties of the IF-CPPQ. Moreover, the participants recruited in the quantitative study included women from across a large number of countries, which increases the external validity of the findings.

There were some limitations of the current thesis. First, one reviewer rather than a team of reviewers conducted the searches for the systematic review (Chapter 3). This may have led to some bias during the study selection process. To reduce possible bias, however, all the articles identified were presented to and discussed with one of the research supervisors (CG). Second, the majority of the women that took part in the qualitative study (Chapter 4)

were interviewed over the phone rather than in person. This could have meant that vital non-verbal communication was missed. Third, the women that took part in the think-aloud study (Chapter 5) were from a fairly young age group, with few women above the age of 50. In addition, all of the participants were heterosexual and a significant proportion of them were students. It would have been useful to explore the perspectives of women from more diverse age groups, sexual orientations, and occupations on their thoughts on the questionnaire items. Finally, the development of the IF-CPPQ did not involve any input from health professionals. Although the focus of the measure is on the impact of CPP from the perspective of women, health practitioners involved in the management and treatment of CPP may have knowledge of additional areas of life that are impacted by CPP.

Future research

There are a number of unanswered questions and directions for future research that arise from this research. This includes the need for studies that investigate the differences between women who respond and those who do not respond to specific treatments for sexual pain. Sexual pain problems are likely to involve multiple mechanisms, some with a clear management pathway, while others may not be as straightforward (Engeler et al., 2016). Further research on mediators of treatment response should be carried out.

Current interventions focus almost exclusively on the individual woman with CPP, despite the accumulating evidence that responses by the male partner may have an impact on women's pain and pain behaviours (Corsini-Munt et al., 2014). Future research should prioritise the development and evaluation of couple therapy approaches. Research on the impact of CPP on couples is very limited and has focussed on sexual functioning rather than on relationships more generally (Bois et al., 2015; Rosen et al., 2014; Smith & Pukall, 2011). It would therefore be beneficial for future research to consider how couples cope with CPP, rather than only focussing on the individual woman.

Future qualitative research should aim to include more women with diverse CPP conditions, as most research has included women with endometriosis, vulvodynia, and dysmenorrhea. The problems as a consequence of CPP discussed by the women in the qualitative study (Chapter 4) were multidimensional and included negative effects on their relationships, sexual functioning, social functioning, general functioning, and occupational

functioning. Including women with various CPP conditions would result in data that is more reflective of women with CPP.

Finally, although there are a number of suggested uses of the IF-CPPQ, more research is needed to determine its ability to detect clinically meaningful changes. The findings from the current thesis have demonstrated the factor structure of the IF-CPPQ, its internal consistency, and convergent and discriminant validity. The questionnaire's ability to detect clinically meaningful changes is important and should be evaluated in future research.

Conclusions

The aims of the current thesis were to explore the experiences of women with CPP and provide a thorough review of research examining different treatments and interventions for women experiencing sexual pain. A new measure that assesses the impact of CPP on women's lives was developed based on findings from qualitative studies of women's experiences of CPP. Findings from the current thesis have informed existing literature in a number of ways.

First, despite the number of interventions reported as effective for women with sexual pain, only a minority of women report complete relief of their pain. The large variability in complete relief of pain after surgery suggests that less invasive treatments should be considered first by women before undergoing surgery. These include physical and psychological therapies, which have shown to be effective long-term treatments and also improve sexual function and psychological adjustment, supporting a biopsychosocial approach to sexual problems. The qualitative interviews with women with CPP highlighted the diverse impact of the pain on virtually every aspect of women's lives. Thus, it is important that health professionals acknowledge how women are affected by their CPP and the ways the pain may affect them emotionally and psychologically. Finally, findings from the qualitative study informed the development of a psychometrically sound measure, the IF-CPPQ. Such a measure is lacking in CPP research and could be a useful measure for understanding how women are affected by CPP and in assessing response to treatment.

Reflexive comments

The process of completing my thesis has been a valuable learning experience. The systematic review allowed me to become more familiar in this area of research and understand what current treatments and therapeutic approaches have been used to treat sexual pain problems in women. I severely underestimated how long conducting the systematic review was going to take. There were so many titles to scan through as well as so many that were shortlisted. Deciding whether to keep certain papers was challenging because although they met the inclusion criteria, the research quality was poor. My supervisors were helpful in helping me decide whether to keep or remove those paper. There was also the worry that I might have missed important papers that did not come up in my searches (though because my search strategy was quite thorough, this was unlikely). I felt a great sense of achievement when I finalised the papers that would be included in the final write up of the systematic review.

The studies in Chapters 4 and 5 have built my confidence in conducting qualitative data analysis and think aloud studies. These studies gave me the opportunity to interact with the women with CPP directly, giving me first hand insight to their experiences. The qualitative study in Chapter 4 in particular increased my awareness of the impact of CPP significantly. The experience would have improved if more of the interviews were conducted in person. Fortunately, the think aloud study in Chapter 5 required all the participants to be interviewed in person, which I definitely preferred over the phone interviews. One thing I did not expect with the think aloud study was to obtain very rich feedback on the early version of the IF-CPPQ. The feedback was very useful and I think dramatically improved the questionnaire.

The quantitative study in Chapter 6 has built my confidence in managing large datasets and conducting advanced statistical analyses. To my surprise, recruitment for this study was the easiest out of all the studies in this thesis. Based on the analyses, the IF-CPPQ is a valid and reliable measure and would be valuable if it was used in future studies. Developing the IF-CPPQ has made me much of aware of the importance of piloting a new measure and the importance of ensuring the items are relevant to the target population. Beforehand, I was not aware of how much work goes into developing a valid and reliable measure. Finally, because of my thesis, I can now critically assess current measures used in research and whether conclusions drawn are based on reliable data.

Appendices

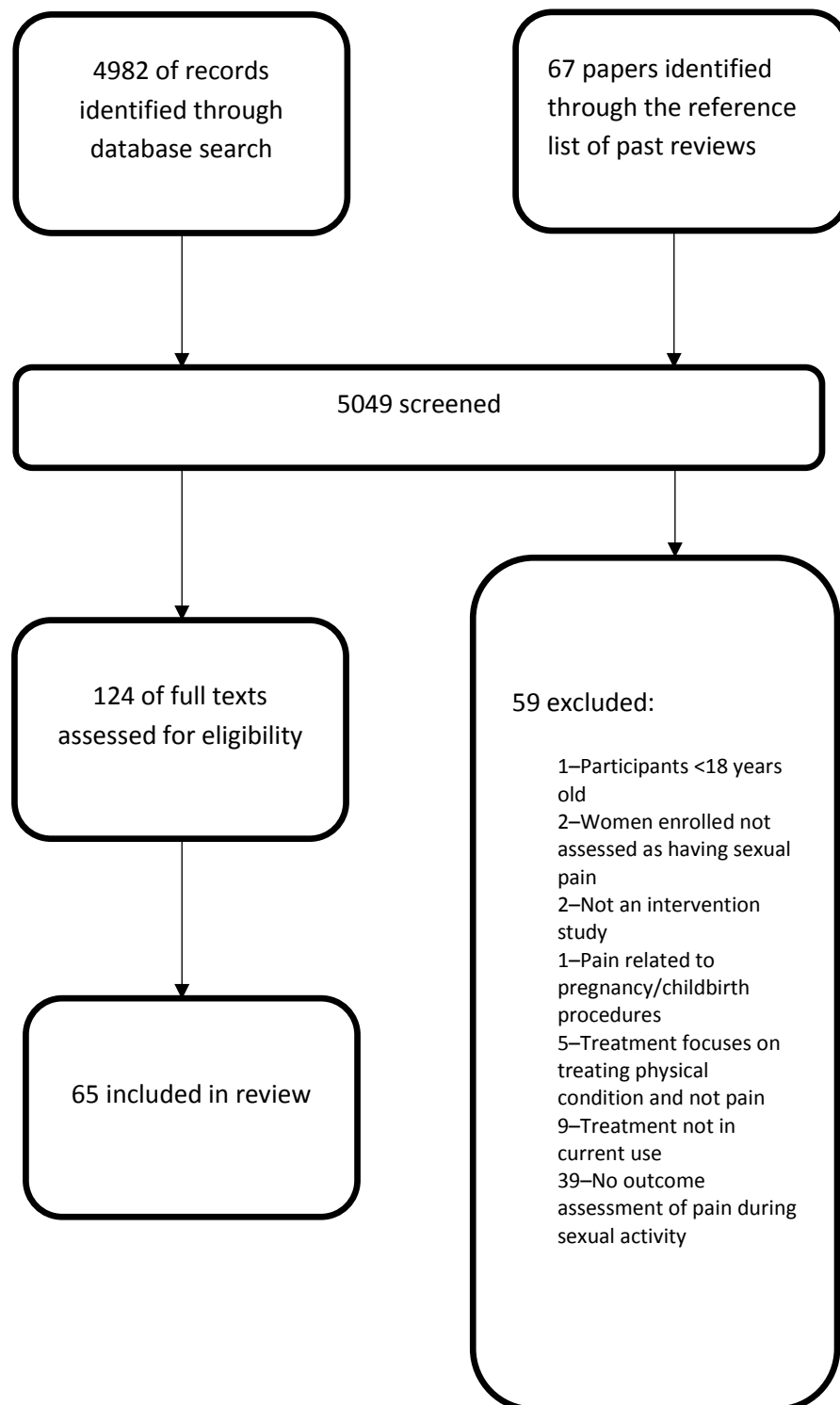
Appendix A: Table 1 Brief description of conditions associated with chronic pelvic pain

Condition name	Description of condition
Endometriosis	A chronic and progressive condition caused when endometrial cells (that are usually found in the uterus) have progressed to other parts of the body e.g. around the abdomen and genito-urinary system (Gilmour et al., 2008)
Vulvodynia	Vulvar discomfort, usually described as burning pain, that occurs in the absence of visible findings or specific, clinically identifiable, neurological disorder (Bornstein et al., 2015).
IBS	The occurrence of chronic or recurrent episodic pain perceived in the bowel that is in the absence of proven infection or other obvious local pathology (Engeler et al., 2016)
Bladder pain syndrome	Also know as interstitial cystitis. The occurrence of persistent or recurrent pain perceived in the urinary bladder region. Other symptoms include pain worsening with bladder filling and day-time and/or night-time urinary frequency. There is no proven infection or other obvious local pathology (Engeler et al., 2016).
Pudendal neuralgia	Damage or irritation to the pudendal nerve (a peripheral nerve in the pelvic region) leading to pain (Engeler et al., 2016)
PID	Caused by an infection of the female upper genital tract (including the uterus, fallopian tubes, and ovaries). PID has been associated with CPP (The Pelvic Pain Support Network, 2014).
Adhesions	Deposits of scar tissue, which can connect organs together. Adhesions usually result from injury and are part of the normal healing process. The abdominal cavity and the pelvis can become injured after surgery or infection, leading to inflammation and the formation of adhesions (Roman et al., 2010).

Note: “IBS” – Irritable bowel syndrome; “PID” – Pelvic inflammatory disease.

Appendix B: Figure 1 Flow of papers during the selection process

(duplicates were automatically removed from the search results by the database). Records refer to the total number of search results retrieved from the databases.



Appendix C: Table 2 Summary of Studies

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Abbott et al. (2006)	CPP	60	Botox (80U at a concentration of 20U/mL); saline solution	Pain; QOL; sexual function	VAS; EQ-5D; SF-12; SAQ	Monthly for 6 mos.	Dyspareunia & pelvic floor muscle tension significantly reduced in both groups	N/A
Baggish (2012)	VV	502	Conservative regimen: (tricyclic antidepressants or Gabapentin; low-oxalate diet (calcium citrate); biofeedback Surgery: Vestibulectomy only or vestibulectomy & paraurethral-duct excision of Bartholin glands	Ability to have pain-free intercourse; vestibular pain	Cotton-tip applicator; self-report	Post-conservative regimen (6 wks); 6 wks posttreatment; 12 wks posttreatment; 6 wks post-surgery, 6 monthly intervals	Conservative regimen: 98 (20%) continued program and had tolerably low pain during intercourse; 305 (61%) able to have intercourse but associated with significant discomfort; 99 (20%) continued to have intolerable pain with intercourse; Cotton-tip applicator touch and pressure: indicated high levels of discomfort ($\geq 8-10/10$) overall success with conservative therapy was 20%	Of the 404 who underwent surgery, 391 were able to have pain-free intercourse (min. follow-up 12 months)

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Ben-Zion et al. (2007)	Vaginismus	32	Surrogate therapy or couples therapy	Experience of pain-free intercourse	Patient self-report	Post-treatment	100% success rate in surrogate compared with 75% in couples group	N/A
Bergeron et al. (1997)	VV	38	Vestibulectomy	Intercourse pain; sexual and couple functioning	Structured telephone interview	Mean 3.3 yrs posttreatment	N/A	Complete relief of pain: 36.8%; great improvement 26.3%; significant increase in intercourse frequency for all patients
Bergeron et al. (2001)	VV	78	GCBT; vestibulectomy; sEMG biofeedback	Pain; sexual pain; sexual function; psychological symptoms	MPQ; Pain rating scale; SHF; DSFI; BSI	Posttreatment; 6 month follow-up	All treatment groups reported statistically significant reductions on pain measures at posttreatment although the vestibulectomy group did significantly better than the GCBT and sEMG groups	Significant reductions in pain and in measures of sexual function and psychological adjustment in all 3 groups, but pain reduction greatest in vestibulectomy group

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Bergeron et al. (2002)	VV	35	Physical therapy, including manual techniques, EMG feedback, electrical stimulation	Pain during intercourse; sexual functioning	Telephone interviews; ratings of pain and questions on sexual functioning	Mean follow-up 16 months (range: 2-44 months)	N/A	Complete or great improvement in 51.4% of sample, moderate improvement for 20.0%, little to no improvement for 28.6%; significant decrease in pain during intercourse and pain during gynaecological examinations; increase in intercourse frequency and in levels of sexual desire and arousal
Bergeron et al. (2008)	PVD	51	GCBT; vestibulectomy; sEMG biofeedback	Pain; sexual pain; sexual function; psychological symptoms	MPQ; Pain rating scale; SHF; DSFI; BSI	2.5 years after previous 6-month follow-up (Bergeron et al., 2001)	N/A	Improvement in all 3 groups was maintained; Patients had less pain at 2.5 year follow-up than at previous 6 month follow-up; no difference in self-reported pain during intercourse between vestibulectomy and GCBT groups
Bergeron et al. (2015)	Dyspareunia	97	CBT therapy; topical steroid	Pain during sexual activity, psychological functioning	MPQ; dyspareunia rating scale; Pain Catastrophizing Scale; Painful Intercourse Self-Efficacy Scale; patient global ratings of improvement	Posttreatment and 6-month follow-up	Significant reductions in pain and psychological adjustment for both groups but GCBT group had greater reductions on pain catastrophizing at posttreatment	Reductions in pain and improvement in sexual function maintained for both groups, but GCBT group showed greater reduction in pain; treatment satisfaction significantly higher in GCBT group

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Bertolasi et al. (2009)	Vaginismus	39	Botox (0.12 mL)	Pain; sexual function; QOL; vaginal spasm and resistance	VAS; FSFI; SF-12; Lamont classification	Week 4 of each treatment cycle	Improvements on all outcome measures 4 wks after first injection; 63.2% “completely recovered”	N/A
Bohm-Stark & Rylander (2008)	PVD	67	Vestibulectomy	Intercourse pain; QOL; psychological wellbeing	Structured questionnaires; VAS	Median follow-up 41 months	N/A	Complete or major improvement in 56% of women with primary PVD and 17% of those with secondary PVD; improved psychological wellbeing reported by 79%
Bornstein et al. (2010)	PVD	30	Nifedipine (0.2% or 0.4%) or placebo	Intensity of pain during intercourse; pain on vestibular touch; pain from speculum insertion	Q-tip test; speculum insertion; study questionnaire	Post-treatment and 3-month follow-up	Mean pain intensity reduced at post-treatment compared with pretreatment for all 3 groups	At 3-month follow-up, improvements in all 3 groups maintained, but nifedipine was not more effective than placebo
Brokenshire et al. (2014)	PVD	30	Vulvar vestibulectomy	Dyspareunia symptoms	Telephone interviews; MDS	Follow-up study of earlier trial	N/A	At 3-year follow-up, 28 patients showed a “complete” response and one showed some improvement

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Brotto et al. (2010)	PVD	29	3 educational seminars	Sexual function; sexual distress; depression; anxiety; psychological symptoms	FSFI; FSDS; BDI; BAI; BSI	Posttreatment and 6-month follow-up	Significant improvements (pre- to post-treatment) in sexual functioning, sexual distress, depression, anxiety, hostility, paranoid ideation, psychoticism, and somatization. No significant improvement in sexual pain scores	Majority of improvements maintained at 6-month follow-up
Corsini-Munt et al. (2014)	PVD	9	12 sessions CBT couple therapy	Pain intensity; sexual functioning; sexual satisfaction; pain-related cognitions; psychological outcomes; treatment satisfaction	MPQ; DISF-SR; numerical rating scale	Posttreatment	Significant improvements in women's pain; improvement in sexuality outcomes for both woman and her partner; some improvement in pain-related cognition, anxiety, and depression for both partners	N/A
Curran et al. (2010)	PVD	8	Acupuncture	Pain; sexual functioning; pain catastrophizing; hypervigilance to pain	FSFI; PCS; PVAQ	Mid-treatment and posttreatment	No significant improvement in pain or ability to have intercourse with treatment	N/A

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Danielsson et al. (2006)	VV	46	EMG biofeedback; topical lidocaine ointment	Pain; sexual functioning; QOL; vestibular pain threshold	VAS; SF-36; vulvalgesimeter; study questionnaire	Posttreatment; 6 month and 12 month follow-up	Not reported	Significant improvements in vestibular pain thresholds, sexual pain, sexual desire, sexual satisfaction in both groups; EMG: 2/18 completely cured, 12/18 improved; Lidocaine: 2/19 completed cured; 10/19 improved
Donders & Bellen (2012)	PVD	30	Cutaneous lysate skin cream; placebo (placebo-controlled crossover trial)	Sexual functioning; tolerability of the treatment; clinical findings	VAS	4 wks and 12 wks	Significant reduction in pain during sexual activity after 4 and 12 wks of treatment in the active cream condition; no change with placebo	N/A
Dykstra & Presthus (2006)	PVD	19	Botox (35 or 50 units) over 8 wks	Pain intensity; QOL; medication use	VAS scale	30 days after treatment or when pain returned to baseline	Significant reduction in pain intensity with both treatments; improvement also in QOL and medication use	N/A
Engman et al. (2010)	Superficial coital pain; vaginismus	59 (44 completed evaluation)	CBT (mean of 14 sessions)	Ability to have intercourse; sexual pain; enjoyment of intercourse; goal fulfilment	Therapy record (VABESC); treatment evaluation questionnaire	Mean follow-up 39 months (range 16-79 mos)	N/A	At follow-up 61% rated their ability to have intercourse without pain, and to enjoy intercourse, as 6 or higher (on a scale from 0-10)

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Farajun et al. (2012)	PVD	40	40 mg enoxaparin; placebo	Pain	Modified BPI; SF-MPQ; VDVQ	Posttreatment; 3-months follow-up	Not reported	Greater reduction in pain during intercourse and vestibular sensitivity in women treated with enoxaparin than in women given placebo
Fenton et al. (2009)	CPP	7	tDCS; sham tDCS	Overall pain; pelvic pain; abdominal pain; pain during intercourse	VAS; validated pain scale	2 wks posttreatment	tDCS significantly more effective than sham treatment at reducing overall and pelvic pain scores but VAS scores for pain or potential pain with sexual activity increased slightly with active treatment	N/A
Foster et al. (2010)	PVD	133	4 arms: placebo cream-placebo tablets; desipramine tablets-placebo cream; placebo tablets-lidocaine cream; desipramine tablets-lidocaine cream. Outcome Variables: Vulvar pain; Pain with intercourse	Vulvar pain; Pain with intercourse	Tampon test; cotton swab test; patient log; SF-MPQ; BPI; BDI; ISS; NPS; POM	Posttreatment (wk 12); post intervention: a 40 wk open-label phase from wk 12 to wk 52	All treatment groups reported substantial pain reduction on tampon test; sexual satisfaction significantly improved with desipramine alone compared with placebo	Participants that received the combination of gabapentin and lidocaine significantly improved on the cotton-swab test; group that received surgery alone significantly improved on the cotton-swab test and SF-MPQ

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Glazer et al. (1995)	VV	33	EMG biofeedback of pelvic floor musculature	Pain; sexual activity	Pain ratings (0-10); incidence of intercourse	6 evaluations; 6-month follow-up	Reduction in pain and increase in the number of women reporting sexual activity at each evaluation; 22 of 28 women who had abstained from intercourse pretreatment had resumed intercourse posttreatment; subjective reports of pain decreased an average of 83%	Improvements were maintained at 6-month follow-up
Glazer et al. (2000)	Dyesthetic vulvodynia	43	sEMG biofeedback	Vulvar pain; daily functioning; dyspareunia; sexual interest; sexual satisfaction; intercourse frequency	Pain ratings (0-10)	Long-term follow-up study; mean follow-up 42 months	N/A	Significant improvements in vulvar and sexual pain; increase in intercourse frequency in those sexually active; 88.4% reported experiencing no vulvar pain since completing treatment
Goetsch (1996)	VVS	12	Simplified surgical revision of the vestibule	Dyspareunia; vestibular tenderness	Self-reported pain; swab-touch test	Follow-up ranged from 6 mos. – 6 yrs	N/A	10 of 12 patients reported complete resolution of vestibular tenderness, 2 others some improvement

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Goetsch (2007)	Dyspareunia	111	Modified superficial vestibulectomy	Pain during intercourse; tenderness	Questionnaire; dilator insertion	3-month follow-up; longer follow-ups (mean 4.2 years) for 86% of the sample	N/A	At 3-month follow-up, 24% reported less dyspareunia, 9% no change, and 3% were worse
Goetsch (2008)	Vestibulodynia	133	Modified superficial vestibulectomy	Pain	Questionnaires	4 time intervals after surgery (mean follow-up 2.8 years)	N/A	68% reported that they no longer had pain during intercourse, 24% reported having reduced pain, 8% reported no improvement, 2% were worse
Goldfinger et al. (2009)	PVD	13	Pelvic floor physical therapy (8 sessions)	Vestibular pain; pressure pain; dyspareunia; sexual functioning; pain cognitions, depression, and anxiety	Intercourse pain ratings; cotton swab test; vulvagesiometer; gynaecological examination; FSFI; PCS; PASS-20; CES-D; STAI-T; Sexual Esteem subscale of SS	Posttreatment and 3-4 months posttreatment	Significant improvements in vestibular pain, pain threshold, dyspareunia, sexual function, pain cognitions, and pain-related anxiety	Significant improvements in sexual pain, overall sexual function, pain cognitions, and pain-related anxiety maintained
Goldstein et al. (2006)	VVS	104	Vestibulectomy	Overall patient satisfaction with surgery; dyspareunia; coital frequency	Phone interview; questionnaire	Mean follow-up 26 months post-surgery	N/A	No sexual pain (52%); 93% were "satisfied" or "very satisfied" with surgery

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Har-Toov et al. (2001)	Vaginismus; VVS	35	Treatment for vaginismus: self-inserted dilators and counselling; VVS treatment protocol initiated if complaints persisted	Ability to have sexual intercourse without pain	Patient self-report	Posttreatment	6 women dropped out and 4 had no concomitant vaginismus; of 25 women who were treated for vaginismus, 12 were able to have intercourse without pain after treatment; 13 still had dyspareunia and underwent VVS protocol (6 of these were able to have intercourse without pain)	N/A
Heyman et al. (2006)	CPP	50	Distension of the pelvic floor or control (counselling)	Pelvic pain; dyspareunia; QOL; mood symptoms; sleep problems	Questionnaire; VAS of pain episodes	Posttreatment	Distension was significantly more effective than counselling at improving all outcome variables	N/A
Jarvis et al. (2004)	CPP & pelvic floor muscle hypertonicity	12	Botox (10 IU/mL; 20IU/mL; 100IU/mL)	Dyspareunia; dysmenorrhoea; non-menstrual pain; QOL; sexual functioning	VAS; SF-12; EQ-5D; SAQ	12 weeks posttreatment	Dyspareunia and dysmenorrhea significantly improved; QOL and non-menstrual pain showed some improvement (but not significant)	N/A

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Kehoe & Luesley (1996)	VV	39	Modified vestibulectomy	Pain	Self-reported treatment response	Mean 10 months post-surgery	N/A	Complete response: 59%; partial response (30%); no response (11%)
Kehoe & Luesley (1999)	VV	57	Modified vestibulectomy	Pain; return to having coitus	Self-reported treatment response	3 months and 12 months post-surgery	N/A	Complete response: 61.1%; partial response (27.8%); no response (11.1%)
Lambert et al. (2012)	VV	61	Vestibulectomy following physical therapy and CBT sessions	Vulvar pain; dyspareunia; ability to have intercourse; sexual satisfaction	VAS; Q-tip test; vaginal dilation; telephone interviews	1-7 years post-surgery	N/A	Significant reductions in pain reported; in 90% intercourse was possible
Lavy et al. (2005)	VV	59	Modified vestibulectomy	Pain	Self-reported treatment response	6 mos. – 10 years post surgery	N/A	Complete response: 73.6%; partial response 13.2%; no response: 13.2%
Masheb et al. (2009)	Vulvodynia	50	CBT; supportive psychotherapy	pain; vestibular tenderness; sexual function; emotional functioning	MPI; MPQ; Cotton-swab rating; FSFI; BDI; PASS	3, 6 mos and 1 year posttreatment	Compared to psychotherapy, CBT resulted in significantly greater improvements in sexual function and pain during intercourse	At one-year follow-up improvements were maintained

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
McDonald & Rapkin (2012)	Generalized vulvodynia	32	Multilevel local anesthetic nerve blockade	Vulvar pain	MPQ; BDI; FSFI	Posttreatment; follow-up contact 2-3 mos. later	26 women completed the study	Significant improvements in vulvar pain but no changes in sexual functioning (FSFI); some improvement on a global satisfaction item about pain during sexual intercourse
McKay et al. (2001)	VV	29	EMG biofeedback	Sexual pain; sexual activity	Pain ratings; reports of sexual activity	Monthly evaluations	N/A	51.7% reported negligible dyspareunia after 4-6 mos. of therapy; 31% still had mild degree of pain; 17.2% no improvement; 69% resumed sexual intercourse
Murina et al. (2004)	VV	33	Topical capsaicin	Dyspareunia; burning; irritation	VAS	After 4, 8, and 16 weeks of treatment	59% reported improvement in symptoms but burning reported as a side effect by all patients	N/A
Murina et al. (2008a)	PVD	15	Vaginal dilators	Dyspareunia; sexual function	FSFI; MDS	Posttreatment	Significant improvements in sexual function and dyspareunia	N/A

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Murina et al. (2008b)	Vestibulodynia	40	TENS; placebo	Sexual function; dyspareunia; pain	FSFI; VAS; SF-MPQ; MDS	Posttreatment; 3 mos. follow-up	Women in TENS group showed significant improvement on all outcome measures; no improvement in placebo group	Improvement in TENS group maintained at follow-up
Murina et al. (2013)	Vestibulodynia	20	TENS (26.7 sessions) in combination with either palmitoylethanolamide (PEA)+ transpolydatin or placebo	Symptoms of irritation and burning; dyspareunia	VAS; MMQ; perception threshold testing	Posttreatment	Dyspareunia scores had reduced significantly in both groups at posttreatment	N/A
Nappi et al. (2003)	Dyspareunia (n=20); vaginismus (n=9) N: 29	29	Electrical stimulation	Dyspareunia; sexual functioning	VAS; FSFI	Posttreatment	Significant reductions in pain and improvement in sexual functioning	N/A
Nesbitt-Hawes et al. (2013)	CPP and pelvic floor muscle overactivity	37	Botox (single vs. repeat injections)	Pain; vaginal pressure	VAS; vaginal manometry	0, 4, 12, & 26 wks after each injection	Significant reduction in dyspareunia (VAS scores) in both groups	N/A
Nyjiresy et al. (2001)	VV	26	Cromolyn powder in acid mantle; placebo cream	Dyspareunia; burning; irritation	0-3 rating scale	Posttreatment	Moderate reductions in symptoms but no significant between-group differences	N/A

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Nyjireshy et al. (2009)	PVD	38	Amitriptiline; Baclofen cream	PVD symptoms; pain; interference of pain in social activities; sexual functioning; sexual satisfaction	Verbal reports of improvement; rating scale for sexual functioning	4-6 weeks; median 33 weeks follow-up	Not reported	29% little or no improvement; 18% moderate improvement; 53% much improvement
Pagano (1999)	VV	230	Protocol involving: simple local measures; treatment of Candida for those Candida-+; Amitriptyline or Carbamazepine; vestibulectomy performed in non-responders	Dyspareunia	MDS	12 mos. – 5 years posttreatment	N/A	Amitriptyline had positive effects in 60% of women and Carbamazepine in 13%; vestibulectomy performed in 22 women and 20 were said to show significant improvement
Palomba et al. (2006)	CPP/Deep dyspareunia	80	LUNA and vaginal uterosacral ligament resection	Pain	VAS	Posttreatment; 6 mos. posttreatment; 12 mos. posttreatment	Both treatments significantly reduced CPP and deep dyspareunia (no between-group differences)	Improvements in both groups maintained
Pelletier et al. (2011)	PVD	20	Botox	Pain; ability to have intercourse; sexual function; QOL	VAS; FSFI; DLQI	3 mos. and 6 mos. posttreatment	80% of the patients significantly improved on pain ratings at 3 mos.	Further improvement in pain at 6 mos. and QOL and sexual functioning also significantly improved

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Peterson et al. (2009)	PVD	64	Botox; placebo (saline)	Pain; sexual functioning; sexual distress; QOL	VAS; FSFI; FSDS; MOS-SF-36	3 mos. and 6 mos. posttreatment	94% completed treatment; significant reduction in pain and sexual function in both Botox and placebo groups; no between-group differences	Improvements maintained in both groups
Pukall et al. (2007)	VVS	8	Hypnosis	Pain; pain catastrophizing; sexual functioning; anxiety; depression; vestibular pain	MPQ; FSFI; BDI; vulvagesiometer	8-12 weeks posttreatment; 6 mos. follow-up	Improvements on all outcome measures; significant reduction in dyspareunia and depression	N/A
Rapkin et al. (2008)	VV	27	Caudal epidural block	Pain; sexual functioning; mood; pressure pain thresholds	MPQ; FSFI; BDI; vulvagesiometer	8-12 weeks after treatment start of treatment; 4-6 mos. posttreatment	Improvements in vestibular pain and dyspareunia	N/A
Schnyder et al. (1998)	Vaginismus	44	2 types of desensitization treatment with dilators: in vivo (physician introduced dilator) and in vitro (patient inserted dilator after physician instructions)	Ability to have intercourse; pain	Daily diaries; follow-up interviews	Posttreatment; follow-up (mean 10 months)	No significant differences between two modes of delivery; 97% able to have intercourse although 50% still experienced some pain during intercourse	50% reported that their vaginismus had disappeared; 47.7% that it had improved

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Spoelstra et al. (2011)	PVD	70	Multidisciplinary treatment approach involving multiple treatments e.g., EMG, sex therapy, physical therapy	Vulvar pain; sexual functioning; sexual distress; relationship quality	VAS; FSFI; FSDS; NRV	3-7 years posttreatment (mean 5 years)	N/A	Significant reduction in vulvar pain, reported by 82% of women; 80% had resumed intercourse, but only 8% reported completely pain-free intercourse
Steinberg et al. (2005)	VV	52	Capsaicin (12 weeks treatment)	Pain; dyspareunia	KTT; MDS	Posttreatment	Significant improvement in dyspareunia and vulvar discomfort	N/A
ter Kuile & Weijnenborg (2006)	VVS	76	CBT (12 sessions)	Dyspareunia; distress; marital satisfaction; perceived ability to control pain	Pain ratings; SCL-90; MMQ; GRISS; CSQ	1 week and 3 months posttreatment	Significant improvements in dyspareunia, sexual satisfaction, vestibular pain, perceived pain control, and vaginal muscle tension	Improvements maintained
ter Kuile et al. (2013)	Vaginismus	70 couples	Therapist-aided exposure or waiting-list control	Intercourse ability	Daily diaries; validated questionnaires on sexual functioning and distress	6 and 12 weeks after start of treatment	Clinical improvement in pain during intercourse, vaginismus, coital fear, and distress; 89% of couples in active treatment group reported having had sexual intercourse posttreatment compared with 11% in the control group	Improvements were maintained at 3-month follow-up

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
Tommola et al. (2011)	VV	57	Modified vestibulectomy	Pain; dyspareunia; sexual wellbeing; complication rates	Swab-touch test; VAS; MWSW	Median 4 yrs post-surgery	N/A	Significant decrease in dyspareunia; posterior vestibular tenderness absent in 64.2%; 91% were satisfied with outcome
Tommola et al. (2012)	VV	66	Modified posterior vestibulectomy or conservative treatment	Ability to have intercourse; dyspareunia; depression; sexual wellbeing; availability of social support	Swab-touch test; VAS; Euro-QOL; BDI; MOSSS; MQSW	Mean follow-up 10 mos.	Dyspareunia decreased significantly in both surgery and conservative treatment groups	Long-term sexual wellbeing did not differ between the two groups
Traas et al. (2006)	VV	126	Vestibulectomy	Ability to have intercourse; dyspareunia; sexual satisfaction	Telephone interview	1-4 years post-surgery (median 37 months)	N/A	At follow-up, 93% of patients could have intercourse compared with 78% pre-surgery; 62% of women reported that intercourse was now "painless"

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variables	Measures	Assessment Points	Initial Outcome	Follow-up
van Lankveld et al. (2001)	Vaginismus; dyspareunia	55 couples (20 with a sexual pain problem)	Cognitive-behavioral bibliotherapy (CBB) with minimal therapist support and wait-list control group	Sexual satisfaction; subjective meaning of sexuality; relationship satisfaction	GRISS; ILKS; MMQ	Posttreatment and 10 weeks follow-up	For women with dyspareunia, CBB was only effective in improving sexual intercourse frequency and self-esteem as a sexual partner; for women with vaginismus, CBB group showed greater improvement than controls in sexual intercourse frequency, vaginismus, anorgasmia, and self-esteem as a sexual partner	Improvements related to frequency of sex and problem-associated distress were not maintained and female participants with dyspareunia reported more vaginal discomfort
Ventolini & Duke (2009)	Vulvodynia	74	Standardized protocol involving 4 steps: vulvovaginal cultures take; dietary modification; oral tricyclics; oral Gabapentin	Ability to have painless intercourse	Pain rating scale	After each step on protocol	81% of patients had improvement	N/A
Yoon et al. (2007)	Intractable genital pain	7	Botox	Pain	VAS	2 weeks posttreatment; follow-up 4-24 mos (mean 11.6 mos)	Subjective pain scores improved	Improvement was maintained

Table 1 Continued

Study	Diagnosis	N	Treatment	Outcome Variable	Measures	Assessment Points	Initial Outcome	Follow-up
Zolnoun et al. (2003)	VV	61	Lidocaine ointment	Pain; ability to have intercourse	VAS; self-reported ability to have intercourse	6-8 weeks after initiation of treatment; 6-month follow-up	Significant improvement in VAS scores; 76% could have intercourse posttreatment compared with 36% pretreatment	77% reported ongoing use of Lidocaine; 20% had sustained improvement in symptoms

Note: BDI Beck Depression Inventory; BAI Beck Anxiety Inventory; BPI: Brief Pain Inventory; BSI Brief Symptom Inventory; CBT Cognitive Behavior Therapy; CES-D The Centre for Epidemiological Studies Depression Scale; CPP Chronic pelvic pain; CSQ Coping Strategy Questionnaire; DLQI Dermatology Life Quality Index; DSFI DeRogatis Sexual Functioning Inventory; DISF-SR DeRogatis Interview for Sexual Functioning-Self-Report (DISF-SR); EQ-5D European Quality of Life Survey; FSDS Female Sexual Distress Scale; FSFI Female Sexual Function Index; GRISS Golombok Rust Inventory of Sexual Satisfaction; GCBT Group Cognitive Behavior Therapy; ILKS: Intimate Bodily Contact Scales; ISS Index of Sexual Satisfaction; KTT Kaufman Touch Test; LUNA Laparoscopic uterine nerve ablation; MDS Marinoff Dyspareunia Scale; MMQ Maudsley Marital Questionnaire; MPI Multidimensional Pain Inventory; MOSSS Medical Study Support Scale; MPQ McGill Pain Questionnaire; MQSW McCoy Questionnaire for Sexual Well-Being; N/A Not applicable; NPS Neuropathic Pain Scale; NRV Dutch Relationship Questionnaire; PASS-20 Pain Anxiety Symptoms Scale; PCS Pain Catastrophizing scale; POMS Profile of Mood States; PVAQ Pain and Vigilance Awareness Questionnaire; PVD Provoked vulvodynia; QoL Quality of life; SAQ Sexual Activity Questionnaire; SF-12 Short-Form-12 Health Survey; SF- MPQ Short Form- McGill Pain Questionnaire; MOS-SF-36 The Medical Outcomes Study Short form-36; SHF Sexual History Form; SS Sexuality Scale; STAI-T The State-Trait Anxiety Inventory Trait Version; sEMG Surface electromyography; tDCS Transcranial direct current stimulation; TENS Transcutaneous electrical nerve stimulation; VABESC Vaginitic Behaviour Scale; VAS – Visual analogue scale; VDVQ Vulvovaginal Disease Vulvodynia Questionnaire; VV Vulvar vestibulitis

Appendix D: Table 3 Risk of Bias Assessment for Each Study

Study	Random sequence generation	Allocation concealment	Blinding of participants	Blinding of outcome assessment	Incomplete outcome data	Selective reporting	Other bias
1. Abbott (2006)	L	?	L	?	L	L	---
2. Baggish (2012)	H	?	H	H	L	L	---
3. Ben-Zion (2007)	?	?	H	H	H	L	H
4. Bergeron (1997)	?	?	H	L	L	H	H
5. Bergeron (2001)	L	?	H	L	L	L	---
6. Bergeron (2002)	?	?	H	H	L	L	---
7. Bergeron (2008)	L	?	H	L	L	L	---
8. Bergeron (2015)	L	?	?	L	H	L	---
9. Bertolasi (2009)	?	?	H	H	L	L	---
10. Bohm-Starke (2008)	?	?	H	H	L	L	H
11. Bornstein (2010)	H	?	L	L	L	L	---
12. Brokenshire (2014)	?	?	H	H	L	L	---
13. Brotto (2010)	?	?	H	H	L	L	---
14. Corsini-Munt (2014)	?	?	H	H	L	L	---
15. Curran (2010)	?	?	H	H	L	L	---
16. Danielsson (2006)	L	?	H	H	H	L	H
17. Donders (2012)	?	?	L	L	L	L	---
18. Dykstra (2006)	?	?	H	H	L	L	H
19. Engman (2010)	?	?	H	H	H	H	---
20. Farajun (2012)	L	L	L	L	L	L	---
21. Fenton (2009)	?	?	L	L	L	L	---
22. Foster (2010)	L	?	L	L	L	L	---
23. Glazer (1995)	?	?	H	H	L	L	---

24. Glazer (2000)	?	?	H	H	L	L	---
25. Goetsch (1996)	?	?	H	H	L	L	H
26. Goetsch (2007)	H	?	H	H	L	L	---
27. Goetsch (2008)	H	?	H	H	L	L	---
28. Goldfinger (2009)	?	?	H	H	L	L	---
29. Goldstein (2006)	?	?	H	H	L	L	H
30. Har-Toov (2001)	?	?	H	H	H	L	---
31. Heyman (2006)	L	?	H	H	L	L	---
32. Jarvis (2004)	H	?	?	H	L	L	---
33. Kehoe (1996)	?	?	H	H	L	L	---
34. Kehoe (1999)	?	?	H	H	L	L	---
35. Lambert (2012)	?	?	H	H	H	L	H
36. Lavy (2005)	?	?	H	H	L	L	---
37. Masheb (2009)	L	L	H	L	L	L	---
38. McDonald (2012)	?	?	H	H	H	L	---
39. McKay (2001)	?	?	H	H	L	L	---
40. Murina (2004)	?	?	H	H	L	L	---
41. Murina (2008)a	?	?	H	H	L	L	---
42. Murina (2008)b	L	?	?	?	L	L	---
43. Murina (2013)	L	?	L	L	L	L	---
44. Nappi (2003)	?	?	H	H	L	L	---
45. Nesbitt-Hawes (2013)	H	H	H	H	L	L	---
46. Nyirjesy (2001)	L	L	L	L	H	H	---
47. Nyirjesy (2009)	?	?	H	H	?	L	---
48. Pagano (1999)	?	?	H	H	L	L	---
49. Palomba (2006)	L	L	?	L	L	L	---
50. Pelletier (2011)	?	?	H	H	L	L	---
51. Peterson (2009)	L	L	L	L	L	L	---
52. Pukall (2007)	?	?	H	H	H	L	---
53. Rapkin (2008)	?	?	H	H	L	L	---
54. Schnyder (1998)	?	?	H	H	H	L	---

55. Spoelstra (2011)	?	?	H	L	L	L	---
56. Steinberg (2005)	?	?	H	H	L	L	---
57. TerKuile (2006)	?	?	H	H	H	L	---
58. Ter Kuile (2013)	L	?	H	L	L	L	---
59. Tommola (2011)	?	?	H	H	H	L	H
60. Tommola (2012)	H	?	H	L	L	L	---
61. Traas (2006)	?	?	H	H	L	L	H
62. van Lankveld (2001)	L	?	H	L	L	H	---
63. Ventolini (2009)	?	?	H	H	L	L	---
64. Yoon (2007)	?	?	H	H	L	L	---
65. Zolnoun (2003)	?	?	H	H	H	L	---

Note: '?' – Unclear risk; 'H' – High risk; 'L' – Low risk; '---' – Not applicable

Appendix E: Information sheet and consent form used in Chapter 4 qualitative study

Exploring the Experience of Pelvic Pain for Women and their Partners Letter of Consent

I am Miznah Al-Abbadey and I am studying PhD health psychology at the University of Southampton. I am requesting your participation in a study aiming to explore how women experience pelvic pain and how pelvic pain affects all aspects of an individual's life and personal relationships. For each participant this will involve an in-depth interview of approximately 1 hour. Personal information will not be released to or viewed by anyone other than researchers involved in this project. Results of this study will not include your name or any other identifying characteristics.

Completion and return of this questionnaire will be taken as evidence of you giving informed consent to be included as a participant in this study, for your data to be used for the purposes of research, and that you understand that published results of this research project will maintain your confidentiality. Your participation is voluntary and you may withdraw your participation at any time.

To request a project summary or have any questions please contact:

Miznah Al-Abbadey at maa1g10@soton.ac.uk

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk

CONSENT FORM

Study title: Exploring the Experience of Pelvic Pain for Women and their Partners Letter of Consent

Researcher name: Miznah Al-Abbadey

Please select the boxes if you agree with the statements:

I have read and understood the information sheet
and will have the opportunity to ask questions about the study

☐

I agree to take part in this research project and agree for my data to
be used for the purpose of this study

☐

I understand my participation is voluntary and I may withdraw
at any time without my legal rights being affected

☐

Please check this box to indicate that you consent to taking part in
this survey.

☐

Thank you for your participation in this research.

Name: _____

Signature _____ Date _____

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email maalg10@soton.ac.uk

Appendix F: Debrief sheet used in Chapter 4 qualitative study

Exploring the Experience of Pelvic Pain for Women and their Partners

Debriefing Statement

The aim of this research was to explore how pelvic pain affects aspects of an individual's life and their personal relationships, as well as how these factors are involved in the experience of pain itself.

Your data will help our understanding of the experience of living with pelvic pain and how it impacts upon every aspect of the individual's life and relationships. Once again results of this study will not include your name or any other identifying characteristics. The research did not use deception. You may have a copy of this summary and a summary of the research findings once the project is completed if you wish.

If you have any further questions please contact me Miznah Al-Abbadey at maalg10@soton.ac.uk

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk

Support

Here is some information about organisations that may be helpful should you need them:

Should you have any health related concerns, you should consider your general practitioner (GP) your first port of call.

If you feel that you would benefit from a counselling service, 'Southampton City Counselling' is a free counselling service based in the centre of Southampton. You can email them on info@southamptoncitycounselling.co.uk

For some information about vulval pain, here's a link to a helpful website:

www.vulvalpainsociety.org/vps/

Appendix G: Poster used to recruit participants for Chapter 4 qualitative study

Exploring the Experience of Pelvic Pain for Women and their Partners

My name is Miznah Al-Abbadey and I am currently a Health Psychology PhD student at the University of Southampton.

My study is based on female pelvic pain and I am interested in exploring the impact of this on the individual's life and aspects of their personal relationships.

I am therefore looking for female volunteers, aged 18 and over who have experienced pelvic pain for a minimum of 3 months and, for those in a current relationship, their partners to participate in in-depth interviews.

Everything discussed in the interviews will be confidential. Interviews can take place at either the University of Southampton, in participant's homes or over the telephone.

If you are an undergraduate student at the University of Southampton, you will be offered 2 credits for your participation.

If you would like to participate in my study, please contact me at maalg10@soton.ac.uk

Exploring the Experience of Pelvic Pain for Women and their Partners. Miznah: maalg10@soton.ac.uk
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Appendix H: Interview Guide used in Chapter 4 qualitative study

Preamble

First of all, I would like to thank you for taking part in my study. My name is Miznah, I am a student from the University of Southampton and this interview is part of my research for my PhD health psychology dissertation project³.

From these interviews I am interested in finding out about how women experience pelvic pain and how the pain affects all aspects of life such as work, self-esteem, socialising and personal relationships. Anything that you could tell me about this during the interview will be interesting and helpful.

Anything you tell me during this interview will be confidential. You will not be referred to by name but as a participant number allocated to you and any names/ locations mentioned during the interview will be edited out of the study and replaced with pseudonyms. Is this OK?

The interview is going to be recorded, is that OK?

If at any time you would like to stop participating in the research, please let me know and I will stop the interview.

Do you have any questions? Are you happy for me to start the recording and begin the interview?

Interview topic guide (women with partners/ if answer to question 2 is yes)

1. So, if it is OK, please tell me a bit about yourself
2. Are you currently in a relationship? *Probe: please tell me a little bit about your relationship? How long have you been together? Could you please tell me a bit about your family situation (married, children)? Age? Partners Age? Do you have any children? (If so how many?)*

Pelvic Pain- If it is Ok with you, we will now discuss pelvic pain.

³ The version of the interview guide used by the MSc student had the following sentence: My name is XXX, I am a student from the University of Southampton and this interview is part of my research for my MSc health psychology dissertation project.

3. Could you please tell me about the pelvic pain that you experience? *Probes: When did it start? Have you had any treatment? Could you describe the pain? How intense is the pain? Have you noticed any patterns or any times when the pain is worse/better? Has the pain changed at all (got worse or stayed the same)?*

Aspects of life

4. Do you think that pelvic pain affects your life in way? How?? (employment, education, friendships, exercise, hobbies, self-esteem)

If yes, what aspects of your life does it affect? Please tell me more about this. How does this make you feel?

Personal Relationship- If it's OK can we talk a bit about pain during intercourse and your relationship?

5. Does the pain affect your sexual relationship? *Probe: How? Tell me in as much detail as you feel comfortable with.*

6. Do you engage in any other non-penetrative sexual activities with your partner (such as foreplay)? *If so, do you experience pain during these?*

7. Do you have sexual intercourse? *Probe: Please tell me more about this? If not, have you tried?*

8. Does your partner know that you experience pelvic pain? *Probe: If yes/no please tell me why. If yes, what happened when you told them? If no, what were the outcomes of this?*

9. Could you tell me about what happens when you experience this pain during intercourse? *Probe: How does this make you feel?*

10. Do you think that this pelvic pain affects your relationship in any other way? *Probe: If yes, please tell me more about this. If no, why do you think this is?*

Interview guide (women without current partner/ have answered no to question 2)

1. So, if it is OK, please tell me a bit about yourself

2. Are you currently in a relationship? *Probe: Could you please tell me a bit about your family situation (Children, living arrangements) Age? Do you have any children? (If so how many?)*

Pelvic Pain- If it is Ok with you, we will now discuss pelvic pain.

3. Could you please tell me about the pelvic pain that you experience? *When did it start? Have you had any treatment? Could you describe the pain? How intense is the pain? Have you noticed any patterns or any times when the pain is worse/better? Has the pain changed at all (got worse or stayed the same)?*

Aspects of life

4. Do you think that pelvic pain affects your life in any way? How?
(employment, education, friendships, exercise, hobbies, self-esteem)

If yes, what aspects of your life does it affect? Please tell me more about this. How does this make you feel?

Personal relationships-- If it's OK can we talk a bit about pain during intercourse and personal relationships?

5. Have you had boyfriends/ sexual partners in the past? *Probe: Please tell me more about this. Has the pain affected any sexual relationships?*

6. Have you engaged in any other non-penetrative sexual activities (such as oral sex)? *Probe: If so, have you experienced pain during these activities?*

7. Have you engaged in intercourse? *If not, have you tried? Do you experience pain?*

8. Have any previous partners known that you experience pain during intercourse? *Probe: If yes/no please tell me more about why i.e. did you have any expectations about how (s)he would respond? If yes, what happened when you told them?*

9. Could you tell me about what has happened in previous relationship(s) when you experienced pain during intercourse? *Probe: Tell me about how that made you feel*

10. Do you think that pelvic pain has affected your personal relationships in any other way? *Probe: Please tell me more about this*

Techniques that will be implemented where appropriate in the interview

- “That is really interesting; can you please tell me more about that?”
- “mmm”
- Nodding
- Pauses
- “Could you please just clarify something for me, what did you mean by...?”

Ending the interview

Thank you very much. What you have said has been really interesting. Is there anything you would like to add before I stop the recording?⁴

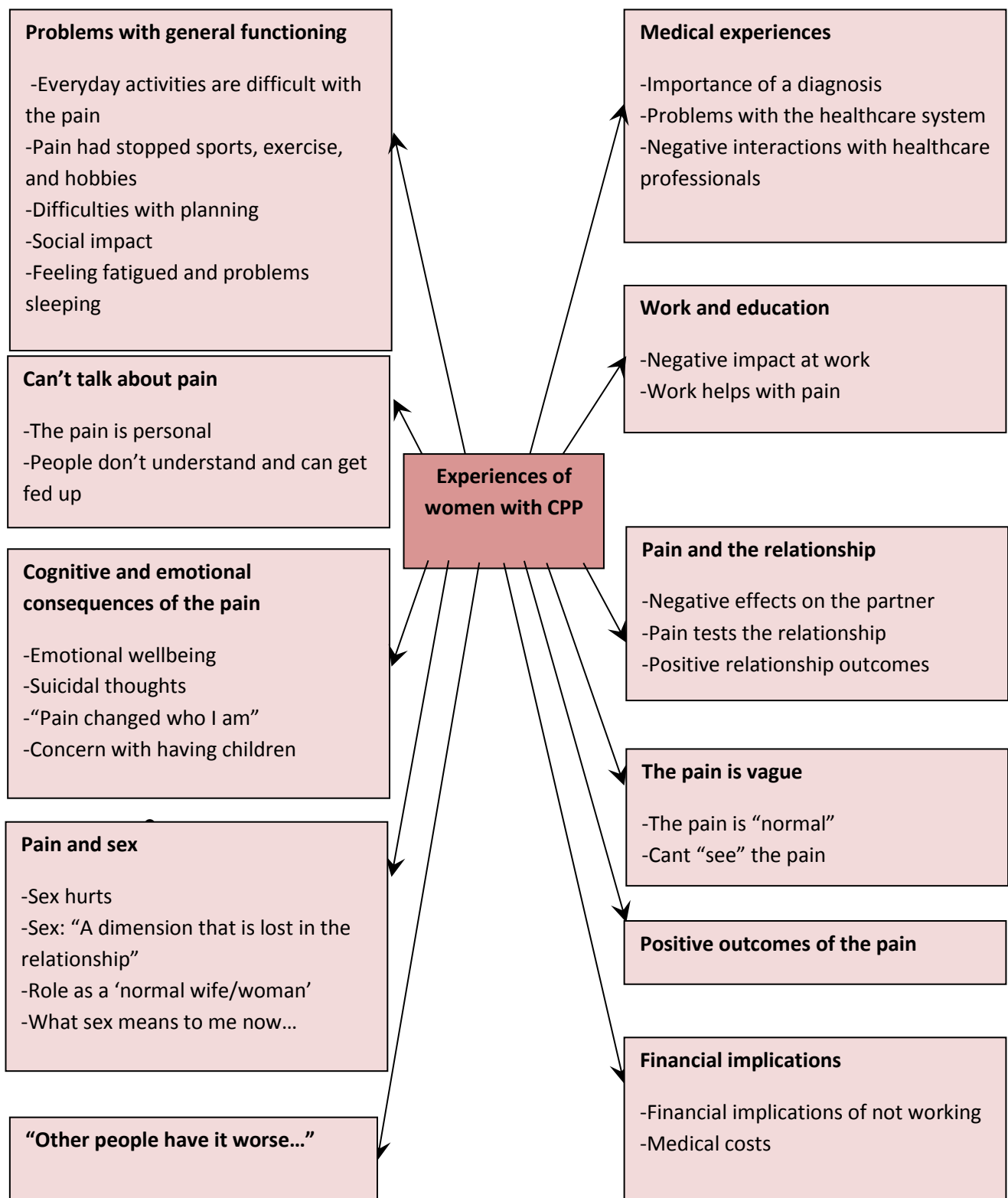
⁴ The interview guide used by the MSc student had additional sections with questions for the partners of the women with CPP. These additional sections were removed from the current interview guide because the study focussed on the experiences of the women themselves and not their partners.

Appendix I: Table 4 Participant background characteristics in Chapter 4 qualitative study

(N = 25)	
Mean age (Range)	36.6 (22-63)
Relationship status (n)	
Single	2
In a relationship	11
Engaged	1
Married	11
Mean years since pain (Range)	8.5 (0.7-29)
Mean years since diagnosis (Range)	4.3 (0.7-17)
CPP diagnoses (n)	
Endometriosis	10
Neuropathic pain/ Pudental neuralgia	2
Vulvodynia	8
IBS	3
Lichen simplex	1
POS	1
IC	1
SPD	1
Chronic pelvic pain syndrome	1
No diagnosis	1
Other diagnoses	
Multiple sclerosis	1
Chronic fatigue	2
Migraines	3
Hypermobility syndrome	1
Low lymphocytes	1
Stress incontinence	1
Asthma	2
Eczema	2
Hay fever	2
Arthritis	1

Note: CPP – Chronic pelvic pain; IBS – Irritable bowel syndrome; IC – Interstitial cystitis; POS – Polycystic ovary syndrome; SPD – Symphysis pubic dysfunction

Appendix J: Figure 2 Thematic map showing main themes and subthemes in Chapter 4 qualitative study



Appendix K: Poster used for Chapter 5 think-aloud study

The Development of an Online Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain (CPP)

(Version 3, 30/07/14, Ethics Number: 11850, End date: 1st December 2014)

A new **questionnaire** that can be used to assess the impact of **CPP** on women's lives has been developed and **we would like women's feedback on the measure.**

The **questionnaire** has been designed specifically for women with CPP and aims to assess factors they consider relevant and important to them.

Are you **female**, aged **18** or over and have experienced **pelvic pain** for a minimum of **3 months**? If yes, you are eligible to take part.

If you agree to take part, you would be required to read through the questionnaire with the researcher and give them your thoughts and opinions on the questions. The sessions will take place at the University of Southampton and last approximately 1 hour.

As a thank you for your time and contribution, you will be **offered** either **£8 or 4 credits** (if you are a University of Southampton student). **All data will be confidential.**

If you would like to participate in my study, please contact Miznah Al-Abbadey at maalg10@soton.ac.uk

The development of a questionnaire for women with chronic pelvic pain. Research email: maalg10@soton.ac.uk
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Appendix L: Participant information sheet used in Chapter 5 think-aloud study

The Development of an Online Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain (CPP) Participant Information Sheet (28/07/14, Version 3)

Researcher: Miznah Al-Abbadey
ERGO Study ID number: 11850

Please read this information carefully before deciding whether to take part in this research. You will need to indicate that you have understood this information before you can continue. You must also be female, aged 18 or over, and have experienced chronic pelvic pain for at least three months to participate.

What is the research about?

The aim of the current study is to pilot a new questionnaire that assesses the impact of chronic pelvic pain on women's lives. The questionnaire will be designed specifically for women with chronic pelvic pain and will assess factors considered relevant and important to them. The aim of the pilot study is to make sure the questionnaire is easy to understand and asks questions that are important to women with chronic pelvic pain.

Why have I been chosen?

Women who have experienced chronic pelvic pain for at least three months are invited to take part. Participants are also required to be fluent in written English.

What will happen to me if I take part?

If you decide to take part, you will be asked to read through the questionnaire with the researcher in a think-aloud interview. During this interview, you will be encouraged to express your thoughts and opinions on the questionnaire as you read through it. The questionnaire will ask about how your chronic pelvic pain has impacted your mood, work, socialising, personal relationships, and daily functioning. You will not be required to fill in the questionnaire, but to read each item and say what you think. On completion, you will be debriefed by the researcher and will be given relevant contact details for further information/resources. The interviews are expected to be approximately one hour long.

Are there any benefits in my taking part?

You will be offered either £8 or 4 credits (if you are a University of Southampton student) as a thank you for taking part. You will also be contributing to research which aims to help women with chronic pelvic pain.

Are there any risks involved?

There are no major risks involved in this research. However, some items will ask personal questions, which can make some people feel uncomfortable and experience some negative emotions. However, you will not be required to answer any of the questions on the questionnaire and the interview data will be anonymised. In addition, you can withdraw from the study at any time without providing a reason.

Will my participation be confidential?

Yes. The study complies with the Data Protection Act/University policy and the information will be stored and remain confidential. Data will be kept on a password-protected computer.

What happens if I change my mind?

If you change your mind you have the right to withdraw at any time without your legal rights being affected.

What happens if something goes wrong?

In the unlikely case of concern or complaint, please contact the chair of the Ethics Committee, Psychology, University of Southampton, SO17 1BJ, UK. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk.

Where can I get more information?

If you would like any more information about the study, please contact one of the research team members:

-Miznah Al-Abbadey (primary researcher) – maalg10@soton.ac.uk

-Dr Cynthia Graham – c.a.graham@soton.ac.uk

-Dr Christina Lioffi – c.liossi@soton.ac.uk

Appendix M: Consent form used in Chapter 5 think-aloud study

CONSENT FORM

Study title: The Development of an Online Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain (CPP)

Researcher name: Miznah Al-Abbadey

Study reference:

Ethics reference:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (24/06/14 Version 1) and have had the opportunity to ask questions about the study.

☐

I agree to take part in this research project and agree for my data to be used for the purpose of this study

☐

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected

☐

I am happy to be contacted regarding other unspecified research projects. I therefore consent to the University retaining my personal details on a database, kept separately from the research data detailed above. The ‘validity’ of my consent is conditional upon the University complying with the Data Protection Act and I understand that I can request my details be removed from this database at any time.

☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name).....

Signature of participant.....

Date.....

Appendix N: Debrief sheet used in Chapter 5 think-aloud study

The Development of an Online Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain (CPP)

Debriefing Statement (Version 1, 24/06/14, ERGO Number: 11850)

Thank you for taking part in this research. The aim of this research was to pilot a new questionnaire that aims to assess the impact of chronic pelvic pain (CPP) on women's lives. It is expected that a new CPP questionnaire will allow for more standardised comparisons between research studies. The information you provided in the interviews will help ensure the questionnaire is clear and asks questions that women with chronic pelvic pain find important and relevant to them. Once again, the results of this study will not include your name or any other identifying characteristics. The study did not use deception. You may have a copy of this summary and/or a summary of the research findings if you wish.

It is not uncommon to experience some anxieties or concerns when completing questionnaires about CPP and support is available. If participating in this study raised any issues for you, the following resources may be helpful:

- Pain UK – www.painuk.org
- Pelvic Pain Support Network - <http://www.pelvicpain.org.uk>
- Women's Health Concern - <http://www.womens-health-concern.org/>
- Vulvar Pain Society - <http://www.vulvalpainsociety.org/vps/>
- Endometriosis UK - <http://endometriosis-uk.org/>

If you have any further questions or concerns, you may also contact the research team members:

Miznah Al-Abbadey (primary researcher) – maalgl0@soton.ac.uk

-Dr Cynthia Graham – c.a.graham@soton.ac.uk

-Dr Christina Lioffi – c.liossi@soton.ac.uk

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, or would like to complain, you may contact the Chair of the Ethics

Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44
(0)23 8059 4663, email slb1n10@soton.ac.uk

Appendix O: Receipt template used to confirm payment to participants in Chapter 5 think-aloud study

Study Receipt / ERGO Study Number: 11850

I confirm that I have received £8 for participating in the pilot study of “The Development of an Online Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain (CPP)”

Researcher

Name:.....
.....

Date:.....
.....

Researcher

Signature:.....
.....

Participant

Name:.....
.....

Date:.....
.....

Participant

Signature:.....
.....

Appendix P: Interview Guide used in Chapter 5 think-aloud study

Before starting the think-aloud

- When did the pain start?
- Where is the pain?
- How does the pain feel?
- how long have you experienced your pain?
- have you seen a doctor?
- How frequent do you feel pain?
- How long does your pain last?
- What investigations have you had?
- Are you taking any medication for your pain? Which ones?
- What else are you trying/have tried to make you feel better with the pain?

Study Introduction

First of all, I would like to thank you for taking part in my study. My name is Miznah, I am a student from the University of Southampton and this interview is part of my research for my PhD health psychology thesis.

I will be conducting a think-aloud interview to pilot a new questionnaire that aims to assess the impact of chronic pelvic pain on women's lives. This will involve you to think out loud as you read the questions. You will not be asked to answer any of the items on the question but only provide your views on the questions. This means you will be asked to say what you are looking at, what you are thinking, how you are feeling, or anything else that comes to mind when you read an item. Try and be as honest and as open as you can. This will help me understand how useful my questionnaire is to women who experience chronic pelvic pain. You will be prompted to say what you are thinking out loud throughout the interview – this does not mean you are doing anything wrong, thinking out loud is not easy and this is just to remind you to think out loud.

Anything you tell me during this interview will be confidential. You will not be referred to by name but as a participant number allocated to you and any names/ locations mentioned during the interview will be edited out of the study and replaced with pseudonyms. Is this OK?

The interview is going to be recorded, is that OK?

If at any time you would like to stop participating in the research, please let me know and I will stop the interview.

Do you have any questions? Are you happy for me to start the recording and begin the interview?

(warm up exercise – count the windows in your home out loud)

Pilot study questions

- What did you think of the questionnaire overall?
- Is there anything you liked about the questionnaire?
- Is there anything you didn't like about the questionnaire?
- Did you feel you were able to understand the questions?
- Did you feel comfortable answering the questions?
- Were the questions worded in a clear way?
- Are the answer choices compatible with your experience?
- Are any questions very difficult to answer?
- How did the questions make you feel?
- Is the questionnaire too long?
- Are there any other important questions that have been missed?

Interview prods

- Can you please clarify what you meant by.....?
- hmmm
- Nodding
- That's interesting, can you please tell me more about that?
- Do you have any suggestions about how this item may be clearer/improved/more relevant?
- Please keep talking
- Tell me what you think/ what are your thoughts?

-What are you thinking right now?

Ending the interview

Thank you so much for your time. Your participation has been very helpful. Is there anything else you would like to add before I stop recording?

Appendix Q: The Impact of Female Chronic Pelvic Pain Questionnaire assessed in Chapter 5 think-aloud study

This questionnaire is intended to be used by adult women who experience chronic pelvic pain as a consequence of any cause. The questionnaire aims to assess the impact of chronic pelvic pain on women's lives in terms of everyday activities (e.g. being able to sit, household tasks, and hobbies), being able to work, socialising, relationships, and sexual relationships.

Questionnaire Items

Thinking about the **past month only**, please indicate how much you agree or disagree with the following statements. The questions **concern your chronic pelvic pain**. Please answer each question with respect to your chronic pelvic pain.

Answer format:

<i>Response categories:</i>	<i>Scoring:</i>
Strongly disagree	0
Disagree	1
Neither agree nor disagree	2
Agree	3
Strongly agree	4

Daily functioning

1. I found it difficult to sit because of the pain
2. I had difficulties with wearing tight-fitting clothes
3. The pain has stopped me from doing everyday activities that I would normally do (e.g. household jobs)
4. I had problems sleeping because of the pain (either falling asleep and/or frequently waking up)
5. I experienced problems walking because of the pain

6. I found it difficult to stand because of the pain
7. I couldn't make plans (e.g. holidays, going out with friends etc.) because of the pain
8. I had to lie down or stay in bed because of the pain
9. The pain has stopped me from doing either sports, exercise, or hobbies
10. I have avoided travel because of the pain

Tiredness

11. I felt tired because of the pain
12. I felt my energy levels were low because of the pain

Work – only for those that are working outside the home

13. I took time off work because of the pain*
14. The pain has negatively affected my performance at work*

Relationship – only for those in a relationship

15. My pain has not been taken seriously by my partner*
16. I felt pressure to be a “normal woman” in my relationship with my partner*
17. I struggled to talk to my partner about my pain*
18. I felt closer to my partner because of my pain*
19. The pain has put a strain on my relationship with my partner*
20. I have had difficulties communicating with my partner about my pain*
21. I felt less connected to my partner because of the pain*

Sex – only for those in a relationship

22. I worried that my partner may satisfy his sexual needs with somebody else*
23. I felt guilty for not being able to have sex*
24. The pain has reduced my ability to feel sexually aroused*

- 25. I have been unable to enjoy sex because of the pain*
- 26. The pain has reduced my desire to engage in sexual intercourse*
- 27. I avoided sexual intercourse because of the pain*
- 28. Sexual activity is very painful (either during or after sexual activity)*
- 29. Sex has become a “task” that I engage in to fulfil my role in my relationship*
- 30. I felt hesitant to tell my partner that sex hurts*
- 31. I have avoided foreplay (sexual activity not involving intercourse) for fear of
this leading to sexual intercourse*
- 32. Foreplay (sexual activity not involving intercourse) feels disappointing*
- 33. Not being able to have sex has made me feel less of a “real woman”*
- 34. I felt frustrated at not being able to have sex*

Relationship – for those not in a relationship

- 35. I have avoided new relationships because of the pain*
- 36. I have been worried that a potential new partner will not understand my pain*
- 37. I don't want to have to talk about my pain to potential new partners*

Sex – for those not in a relationship

- 38. I felt anxious about experiencing pain during sex in future relationships*
- 39. I have been anxious about being pressured into having sex with future
partners*
- 40. I have avoided new relationships because sexual activity has hurt in the past*

Socialising

- 41. I have been unable to attend social events because of the pain
- 42. I have lost friends because of the pain
- 43. I have felt socially isolated because of the pain

44. I have felt socially anxious because of the pain

45. I have not wanted to see anyone because of the pain

Medical

46. I felt frustrated because treatments have not worked

47. I felt “fobbed off” by my doctor or health professional

Suicidal thoughts

48. I have had thoughts about ending my life because of the pain

Self-esteem

49. I felt negative about my body because of the pain

50. The pain has made me feel less confident with myself

51. My pain has made me feel inadequate

Low mood

52. I felt despair about my pain

53. I experienced low mood because of the pain

54. I have gotten upset easily

55. I have not enjoyed things I used to enjoy because of the pain

56. I felt sad because of the pain

57. I felt unmotivated

Other negative emotions

58. I felt angry because of the pain

59. I felt irritable or snappy

60. I felt embarrassed about my pain

Difficulty talking about the pain

61. I felt that I have not been heard or listened to by people close to me

62. I have had difficulties being able to talk about my pain

63. I felt people are fed up hearing about my pain

Future

64. I felt concerned about the possibility of experiencing my pain for the rest of my life

Financial

65. The cost of buying new comfortable clothes has been difficult to deal with

66. The costs of treatments (medicines and/or therapies) for the pain has led to financial strain

Positive outcomes

67. My pain has made me emotionally stronger

68. My experience of pain has motivated me to help others with similar conditions

69. My pain has made me more understanding of others with similar conditions

Out of control

70. I felt controlled by my pain

71. I felt that my pain has taken away my life

Miscellaneous

72. I felt unable to cope with my pain (from qualitative study and adapted from Endometriosis Health profile-30, Jones et al. 2001)

*indicates that these questions will have an additional response option – “Not applicable because: I do not work outside of the home/ I am not currently in a relationship/ I am not currently engaging in sexual activity/ I am currently in a relationship” (the latter half of the response option depends on the question).

Appendix R: Demographic questionnaire used in Chapter 5 think-aloud study and Chapter 6 questionnaire study

Demographic Information

1) What is your age?

2) What is your ethnicity?

a) Black or Black British

b) White

c) Asian or Asian British

d) Mixed

e) Other ethnic groups

3) What is your religious affiliation? Please check only one box.

Christian

Muslim

Jewish

Hindu

Sikh

Agnostic

Atheist

Any other religion

No religious affiliation

Prefer not to say

4) Are you currently working?

Yes, full time

Yes, part time

Not currently working outside the home

5) Are you currently a student?

Yes, full time Yes, part time Not a student

6) Please state your highest educational level:

None

GCSE/O-Level or equivalent

A-Levels or equivalent

Bachelor's degree or equivalent

Postgraduate degree or equivalent

Doctorate

Don't know

7) What is your relationship status?

Single In an exclusive/committed relationship In a casual relationship

8) What is your marital status?

Single Married Divorced/separated Widowed

9) How long have you experienced your pain?

Years: Months:

10) Have you been diagnosed with any of the following? Please tick all those that apply.
Endometriosis

Vulvodynia

Polycystic ovary syndrome

Pelvic organ prolapse

Pelvic adhesions

Interstitial cystitis

Irritable bowel syndrome

Pudendal neuralgia

Pelvic inflammatory disease

No diagnosis/unknown

Other, please state

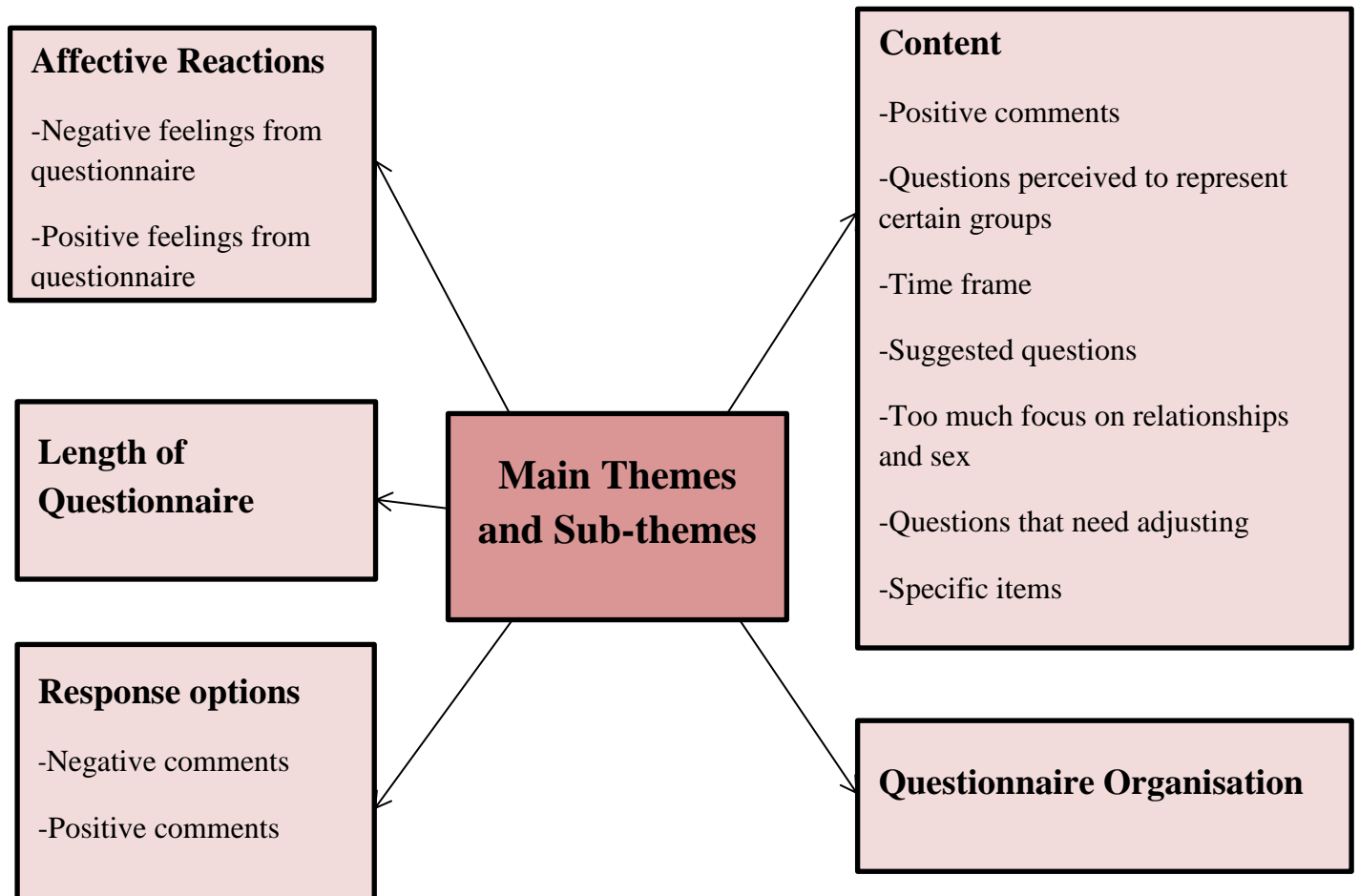
Appendix S: Table 5 Participant background characteristics in Chapter 5 think-aloud study

<i>(n = 10)</i>	
Mean age (Range)	31.3 (22-61)
Relationship status (n)	
Single	1
In an exclusive/committed relationship	8
In a casual relationship	1
Marital status (n)	
Single	6
Married	3
Divorced/separated	1
Widowed	0
Mean years since pain (Range)	7 (0.83-14)
CPP diagnoses (n)	
Endometriosis	4
Vulvodynia	4
POS	1
Pelvic organ prolapse	2
Pelvic adhesions	1
IC	1
IBS	2
Neuropathic pain/ Pudental neuralgia	1
Adenomyosis	1
No diagnosis	2
Occupational status (n)	
Full-time	1
Part-time	5
Not currently working outside the home	4
Student (n)	
Full-time	6
Part-time	1

Not a student	3
Highest education level (n)	
Bachelor's degree or equivalent	5
Postgraduate degree or equivalent	5

Note: Participants could indicate whether they had more than one diagnosis; IBS – Irritable bowel syndrome; IC – Interstitial cystitis; POS – Polycystic ovary syndrome

Appendix T: Figure 3 Chapter 5 think aloud thematic map



Appendix U: Table 6 Items that have been deleted and reasons for deletion after Chapter 5 think-aloud study

Item	Reasons for deletion
11- I felt tired because of the pain	This item was perceived to be too similar to item 12-“I felt my energy levels were low because of the pain”. Participants tended to prefer item 12 compared to item 11.
16-I felt pressure to be a “normal woman”	The word “normal” was seen as offensive to some participants.
17-I struggled to talk to my partner about my pain	This item was perceived to be too similar to item 20-“I have had difficulties communicating with my partner about my pain”. Participants tended to prefer item 20 compared to item 17.
22- I worried that my partner may satisfy his sexual needs with somebody else	Item is more reflective of relationship issues that are likely not specific to women with CPP conditions.
29- Sex has become a “task” that I engage in to fulfil my role in my relationship	Item is more reflective of relationship issues that are likely not specific to women with CPP conditions.
30- I felt hesitant to tell my partner that sex hurts	Item moves away from the focus of the impact of CPP on the individual and asks about a secondary impact of the pain.
31- I have avoided foreplay (sexual activity not involving intercourse) for fear of this leading to sexual intercourse	Item is too specific on how the pain may impact sexual functioning.

32- Foreplay (sexual activity not involving intercourse) feels disappointing	This item was unclear and misinterpreted. Item does not provide any added value.
33- Not being able to have sex has made me feel less of a “real woman”	The word “real” was seen as offensive by some participants.
36- I have been worried that a potential new partner will not understand my pain	No added value from item.
37- I don't want to have to talk about my pain to potential new partners	No added value from item.
39- I have been anxious about being pressured into having sex with future partners	Item moves away from the focus of the direct impact of CPP.
40- I have avoided new relationships because sexual activity has hurt in the past	No added value from item.
41- I have been unable to attend social events because of the pain	Item was perceived to be similar to item 7-“I couldn't make plans (e.g. holidays, going out with friends etc.) because of the pain”. No added value from item.
46- I felt frustrated because treatments have not worked	Item moves away from the focus of the impact of CPP and is asking about the quality of treatments.
47- I felt “fobbed off” by my doctor or health professional	Item moves away from the focus of the impact of CPP and is asking about experiences with health professionals.
51- My pain has made me feel inadequate	Item is vague, No added value from item.

56- I felt sad because of the pain	Item perceived as similar to item 53-“I experienced low mood because of the pain”.
62- I have had difficulties being able to talk about my pain	No added value from question
63- I felt people are fed up hearing about my pain	Item reflects the impact on those in the participant’s life rather than the impact of the pain on the participant.
65- The cost of buying new comfortable clothes has been difficult to deal with	Item not seen to reflect the impact of the pain.
68- My experience of pain has motivated me to help others with similar conditions	Item does not reflect those with CPP conditions.

Note: CPP – Chronic pelvic pain

Appendix V: Table 7 Changes made to items and new items after Chapter 5 think-aloud study

Item	Notes/ Changes made	Updated item
2-I had difficulties with wearing tight-fitting clothes	Needed to be more specific to pain	I had difficulties with wearing tight-fitting clothes because of the pain
5-I experienced problems walking because of the pain AND 6-I found it difficult to stand because of the pain	Combined items	I experienced problems walking or standing because of the pain
7-I couldn't make plans (e.g. holidays, going out with friends etc.) because of the pain	Needed to also include "cancelling plans"	I had to cancel or couldn't make plans (e.g. holidays, going out with friends etc.) because of the pain
9-The pain has stopped me from doing either sports, exercise, or hobbies	Too many components in item. Deleted "sport".	The pain has stopped me from doing either exercise, or hobbies
10-I have avoided travel because of the pain	Needed to clarify type of travel	I have avoided long distance travel because of the pain
13-I took time off work because of the pain	Needed to clarify if studying and volunteering is also included in the question	I took time off work (including any voluntary work or education) because of the pain
14-The pain has negatively affected my performance at work	Needed to clarify if studying and volunteering is also included in the question	The pain has negatively affected my performance at work (including any

voluntary work or
education)

23- I felt guilty for not being able to have sex	Needed to be clearer by referring to pain	I felt guilty for not being able to have sex because of the pain
24- The pain has reduced my ability to feel sexually aroused	Needed to be clearer by specifying whether it refers to sexual encounters with partner or general ability to feel aroused	The pain has reduced my ability to feel sexually aroused (either during partnered sexual activity or during masturbation)
25- I have been unable to enjoy sex because of the pain	Unclear type of sexual activity item referred to	I have been unable to enjoy sexual activity because of the pain
26- The pain has reduced my desire to engage in sexual intercourse	Unclear type of sexual activity item referred to	The pain has reduced my desire to engage in sexual activity
27- I avoided sexual intercourse because of the pain	Unclear type of sexual activity item referred to	I avoided sexual activity because of the pain
35- I have avoided new relationships because of the pain	Unclear type of relationship item referred to	I have avoided new relationships with potential partners because of the pain
42- I have lost friends because of the pain	Word “lost” perceived as too strong a term	I have been unable to maintain contact with friends because of the pain
44- I have felt socially anxious because of the pain	Clarified meaning of term “socially anxious”	I have felt anxious or “on edge” during social situations because of the pain

54- I have gotten upset easily	Needed to be clearer by referring to pain	I have gotten upset easily because of the pain
57- I felt unmotivated	Needed to be clearer by referring to pain	I felt unmotivated because of the pain
59- I felt irritable or snappy	Needed to be clearer by referring to pain	The pain has made me feel irritable or snappy
61- I felt that I have not been heard or listened to by people close to me	Needed to be clearer by referring to pain	I felt that I have not been "heard" or listened to by people close to me when I have talked about the pain
66- The costs of treatments (medicines and/or therapies) for the pain has led to financial strain	Needed to clarify that item includes all kinds of treatments such as complementary treatments	The costs of treatments, therapies, or remedies for the pain has led to financial strain

Appendix W: Table 8 showing organisations contacted to recruit participants for the Chapter 6 questionnaire study

		Responded?	
	Organisations/Charities	Yes	Have agreed to advertise?
UK	-Pain UK - andy@painuk.org / 0207 8705683 / info@painuk.org	X	NO
	-Women's Health Concern - bhalstead@womens-health-concern.org (Barbara)	X	NO
	-Pain relief foundation - http://www.painrelieffoundation.org.uk/		NO
	-Vulvar Pain Society	X	YES
	-Verity – PCOS - http://www.verity-pcos.org.uk/		NO
	-Pelvic Pain Support Network - info@pelvicpain.org.uk (Judy)	X	YES
	-Endometriosis UK - admin@endometriosis-uk.org (Fiona)/ 020 7222 2781	X	YES
	-Pain Concern - http://painconcern.org.uk/	X	YES
	-Action on pain - http://www.action-on-pain.co.uk/ Email: aopisat@btinternet.com		NO

	-Pain Support - http://www.painsupport.co.uk/	X	YES
	The cystitis and overactive bladder foundation - www.cobfoundation.org	X	YES
	The IBS network - www.theibsnetwork.org	X	NO
Ireland	-Endometriosis association of Ireland - http://www.endometriosis.ie/contact-us/		
	-Chronic pain Ireland - http://www.chronicpain.ie/	X	NO
New Zealand	-Endometriosis new Zealand - http://www.nzendo.org.nz/about-us	X	YES
Australia	-Pelvic pain foundation of Australia - http://www.pelvicpain.org.au/about/pelvic-pain-foundation-australia/	X	NO
U.S.A	International Pelvic Pain Society - info@pelvicpain.org		YES
	National Vulvodynia Association - www.nva.org	X	NO
	Interstitial Cystitis Association - www.ichelp.org	X	YES
Facebook Groups	Endometriosis Awareness		YES
	PCOS Awareness		YES
	Vulvodynia Support	X	YES

Appendix X: Poster used in Chapter 6 questionnaire study

The Development of an Online Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain (CPP) (Version 3 / Ethics Number: 14783 / End Date: 31/08/15)

A new **questionnaire** that can be used to assess the impact of **CPP** on women's lives has been developed and we would like women's feedback on the measure.

The **questionnaire** has been designed specifically for women with CPP and aims to assess factors they consider relevant and important to them. A new **questionnaire** is needed to ensure standardised comparisons between research studies and to assess outcomes of interventions for women with **CPP**.

Are you **female**, aged **18** or over and have experienced **pelvic pain** for a minimum of **3 months**? If yes, you are eligible to take part.

If you agree to take part, you would be required to fill out a series of questions online.

Questions will ask about how your pelvic pain has impacted your life as well as your mood and general wellbeing. The study should take approximately 20 minutes to complete. **All data will be confidential.**

If you would like to participate in my study, please either contact Miznah Al-Abbadey at maalg10@soton.ac.uk or follow this link:

<https://www.isurvey.soton.ac.uk/11632>

The development of a questionnaire for women with chronic pelvic pain. Research email: maalg10@soton.ac.uk , study link: https://www.isurvey.soton.ac.uk/11632
The development of a questionnaire for women with chronic pelvic pain. Research email: maalg10@soton.ac.uk , study link: https://www.isurvey.soton.ac.uk/11632
The development of a questionnaire for women with chronic pelvic pain. Research email: maalg10@soton.ac.uk , study link: https://www.isurvey.soton.ac.uk/11632xxxx
The development of a questionnaire for women with chronic pelvic pain. Research email: maalg10@soton.ac.uk , study link: https://www.isurvey.soton.ac.uk/11632
The development of a questionnaire for women with chronic pelvic pain. Research email: maalg10@soton.ac.uk , study link: https://www.isurvey.soton.ac.uk/11632
The development of a questionnaire for women with chronic pelvic pain. Research email: maalg10@soton.ac.uk , study link: https://www.isurvey.soton.ac.uk/11632xx
The development of a questionnaire for women with chronic pelvic pain. Research email: maalg10@soton.ac.uk , study link: https://www.isurvey.soton.ac.uk/11632

Appendix Y: Table 9 Pain questions used in Chapter 6 questionnaire study

Question	EFA	CFA	Overall dataset
<i>N</i> :	483	486	969
	\bar{x} (SD)	\bar{x} (SD)	\bar{x} (SD)
How would you rate your current pain level?	5.59 (2.43)	5.08 (2.42)	5.33 (2.43)
How would you rate your pain at its worst over the past month?	8.29 (1.62)	7.85 (1.97)	8.07 (1.82)
How would you rate your pain at its best over the past month?	3.46 (2.54)	3.13 (2.46)	3.29 (2.51)
<i>N</i> :	119	156	275
If the past month was not a typical one, how would you rate your average experience of pain over a typical month?	6.61 (1.92)	6.42 (2.31)	6.50 (2.15)

Note: Scores on these questions ranged from “0 – No Pain” to “10 – Worst imaginable pain”.

Appendix Z: 52 item IF-CPPQ used at start of Chapter 6 questionnaire study

This questionnaire is intended to be used by adult women who experience chronic pelvic pain. The questionnaire aims to assess the impact of chronic pelvic pain on women's lives in terms of everyday activities (e.g. being able to sit, household tasks, and hobbies), being able to work, socialising, relationships, and sexual relationships.

Thinking about the past month only, please indicate how much you agree or disagree with the following statements. The questions concern your chronic pelvic pain. Please answer each question with respect to your chronic pelvic pain.

Answer format:

<i>Response categories:</i>	<i>Scoring:</i>
Strongly disagree	0
Disagree	1
Neither agree nor disagree	2
Agree	3
Strongly agree	4

- 1) I experienced problems walking or standing because of the pain
- 2) I have had problems with concentration because of the pain
- 3) The costs of treatments, therapies, or remedies for the pain has led to financial strain*
- 4) The pain has put a strain on my relationship with my partner*
- 5) I found it difficult to sit because of the pain
- 6) I felt embarrassed about my pain
- 7) I had to lie down or stay in bed because of the pain
- 8) I have had difficulties communicating with my partner about my pain*
- 9) I felt controlled by my pain
- 10) I had difficulties with wearing tight-fitting clothes because of the pain
- 11) I have felt socially isolated because of the pain
- 12) The pain has stopped me from doing everyday activities that I would normally do
- 13) I felt unable to cope with my pain

- 14) I felt less connected to my partner because of the pain*
- 15) I felt despair about my pain
- 16) I have avoided sexual activity because of the pain*
- 17) I have avoided long distance travel because of the pain*
- 18) I have gotten upset easily because of the pain
- 19) My pain has made me more understanding of others with similar conditions
- 20) I felt that my pain has taken away my life
- 21) Sexual activity has been very painful (either during or after sexual activity)*
- 22) The pain has made me feel less confident
- 23) I took time off work (including any voluntary work or education) because of the pain*
- 24) The pain has reduced my ability to feel sexually aroused (either during partnered sexual activity or during masturbation)*
- 25) I have not wanted to see anyone because of the pain
- 26) I experienced low mood because of the pain
- 27) I have avoided new relationships with potential partners because of the pain*
- 28) I have felt negatively judged at work because of my pain*
- 29) I felt negative about my body because of the pain
- 30) The pain has stopped me from doing either exercise or hobbies
- 31) I have had thoughts about ending my life because of the pain
- 32) The pain has reduced my desire to engage in sexual activity*
- 33) I felt closer to my partner because of my pain*
- 34) I have been unable to maintain contact with friends because of the pain
- 35) I felt irritable or snappy because of the pain
- 36) I have been unable to enjoy sexual activity because of the pain*
- 37) I felt my energy levels were low because of the pain
- 38) I felt angry because of the pain
- 39) My pain has not been taken seriously by my partner*
- 40) I have felt anxious or "on edge" during social situations because of the pain
- 41) I had problems sleeping because of the pain (either falling asleep and/or frequently waking up)
- 42) I felt anxious about experiencing pain during sexual activity in future relationships *
- 43) I felt that I have not been "heard" or listened to by people close to me when I have talked about my pain

- 44) The pain has negatively affected my performance at work (including any voluntary work or education)*
- 45) I had to cancel or couldn't make plans (e.g. holidays, going out with friends etc) because of the pain
- 46) I felt guilty for not being able to engage in sexual activity because of the pain*
- 47) The pain has stopped me from being able to spend time with my family
- 48) I felt concerned about the possibility of experiencing my pain for the rest of my life
- 49) I have not enjoyed things I used to enjoy because of the pain
- 50) I felt frustrated at not being able to engage in sexual activity*
- 51) I felt unmotivated because of the pain
- 52) My pain has made me emotionally stronger

*indicates that these questions had an additional response option – “Not applicable”

Appendix AA: Additional questionnaires used to validate the IF-CPPQ in Chapter 6 questionnaire study

ERGO Number: 11850

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)

Check the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over you replies: your immediate is best.

A: I feel tense or 'wound up':

Most of the time

A lot of the time

From time to time, occasionally

Not at all

B: I still enjoy the things I used to enjoy:

Definitely as much

Not quite so much

Only a little

Hardly at all

A: I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly

Yes, but not too badly

A little, but it doesn't worry me

Not at all

D: I can laugh and see the funny side of things:

As much as I always could

Not quite so much now

Definitely not so much now

Not at all

A: Worrying thoughts go through my mind:

A great deal of the time

A lot of the time

From time to time, but not too often
Only occasionally

D: I feel cheerful:

Not at all
Not often
Sometimes
Most of the time

A: I can sit at ease and feel relaxed:

Definitely
Usually
Not often
Not at all

D: I feel as if I am slowed down:

Nearly all the time
Very often
Sometimes
Not at all

A: I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all
Occasionally
Quite often
Very often

D: I have lost interest in my appearance

Definitely
I don't take as much care as I should
I may not take as much care
I take just as much care as ever

A: I feel restless as I have to be on the move:

Very much indeed

Quite a lot

Not very much

Not at all

D: I look forward with enjoyment to things:

As much as I ever did

Rather less than I used to

Definitely less than I used to

Hardly at all

A: I get sudden feelings of panic:

Very often indeed

Quite often

Not very often

Not at all

D: I can enjoy a good book or radio or TV program:

Often

Sometimes

Not often

Very seldom

The Dyadic Sexual Communication Scale (DSC) (Catania, 2011)

The following is a list of statements different people have made about discussing sex with their primary partner. Please indicate how much you agree or disagree with each statement.

1. My partner rarely responds when I want to talk about our sex life

1

2

3

4

5

6

Disagree

Agree

Strongly

Strongly

2. Some sexual matters are too upsetting to discuss with my sexual partner.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

3. There are sexual issues or problems in our sexual relationship that we have never discussed.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

4. My partner and I never seem to resolve our disagreements about sexual matters.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

5. Whenever my partner and I talk about sex, I feel like she or he is lecturing me.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

6. My partner often complains that I am not very clear about what I want sexually.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

7. My partner and I have never had a heart to heart talk about our sex life.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

8. My partner has no difficulty in talking to me about his or her sexual feeling and desires.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

9. Even when angry with me, my partner is able to appreciate my views on sexuality.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

10. Talking about sex is a satisfying experience for both of us.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

11. My partner and I can usually talk calmly about our sex life.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

12. I have little difficulty in telling my partner what I do or don't do sexually.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

13. I seldom feel embarrassed when talking about the details of our sex life with my partner.

1	2	3	4	5	6
Disagree					Agree
Strongly					Strongly

The Female Sexual Distress Scale – Revised (FSD-R) (Derogatis et al., 2011)

Below is a list of feelings and problems that women sometimes have concerning their sexuality. Please read each item carefully, and circle the number that best describes **HOW OFTEN THAT PROBLEM HAS BOTHERED YOU OR CAUSED YOU DISTRESS DURING THE PAST 30 DAYS INCLUDING TODAY**. Circle only one number for each item.

How often did you feel:

1. Distressed about your sex life?
Never Rarely Occasionally Frequently Always
2. Unhappy about your sexual relationships
Never Rarely Occasionally Frequently Always
3. Guilty about sexual difficulties
Never Rarely Occasionally Frequently Always
4. Frustrated by your sexual problems
Never Rarely Occasionally Frequently Always
5. Stressed about sex
Never Rarely Occasionally Frequently Always
6. Inferior because of sexual problems
Never Rarely Occasionally Frequently Always
7. Worried about sex
Never Rarely Occasionally Frequently Always
8. Sexually inadequate
Never Rarely Occasionally Frequently Always
9. Regrets about your sexuality

Never	Rarely	Occasionally	Frequently	Always
10. Embarrassed about sexual problems				
Never	Rarely	Occasionally	Frequently	Always
11. Dissatisfied with your sex life				
Never	Rarely	Occasionally	Frequently	Always
12. Angry about your sex life				
Never	Rarely	Occasionally	Frequently	Always
13. Bothered by low sexual desire				
Never	Rarely	Occasionally	Frequently	Always

The Pain Disability Index (Ferrero et al., 2001)

The rating scales below are designed to measure the degree to which several aspects of your life are presently disrupted by chronic pain. In other words, we would like to know how much your pain is preventing you from doing what you would normally do, or from doing it as well as you normally would. Respond to each category by indicating the *overall* impact of pain in your life, not just when the pain is at its worst.

For each of the 7 categories of life activity listed, please circle the number on the scale which describes the level of disability you typically experience. A score of 0 means no disability at all, and a score of 10 signifies that all of the activities in which you would normally be involved have been totally disrupted or prevented by your pain.

1) Family/home responsibilities

This category refers to activities related to the home or family. It includes chores or duties performed around the house (e.g. yard work) and errands or favours for other family members (e.g. driving children to school).

0	1	2	3	4	5	6	7	8	9	10
No										Total
disability										disability

2) Recreation

This category includes hobbies, sports, and other similar leisure time activities.

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

No disability	Total disability
------------------	---------------------

3) Social activity

This category refers to activities which involve participation with friends and acquaintances other than family members. It includes parties, theatre, concerts, dining out, and other social functions.

0	1	2	3	4	5	6	7	8	9	10
No disability										Total disability

4) Occupation

This category refers to activities that are part of or directly related to one's job. This includes non-paying jobs as well, such as that of a housewife or volunteer.

0	1	2	3	4	5	6	7	8	9	10
No disability										Total disability

5) Sexual behaviour

This category refers to the frequency and quality of one's sex life.

0	1	2	3	4	5	6	7	8	9	10
No disability										Total disability

6) Self-care

This category includes activities which involve personal maintenance and independent daily living (e.g. taking a shower, driving, getting dressed, etc)

0	1	2	3	4	5	6	7	8	9	10
No disability										Total disability

7) Life-support activity

This category refers to basic life-supporting behaviours such as eating, sleeping, and breathing.

0	1	2	3	4	5	6	7	8	9	10
No disability										Total disability

The World Health Organisation Quality of Life (WHOQoL) – BREF (The WHOQOL Group, 1998)

The following questions ask how you feel about your quality of life, health, or other areas of your life. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks**.

1. How would you rate your quality of life?

Very poor	Poor	Neither poor nor good	Good	Very good
-----------	------	-----------------------	------	-----------

2. How satisfied are you with your health?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
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The following questions ask about **how much** you have experienced certain things in the last four weeks.

3. To what extent do you feel that physical pain prevents you from doing what you need to do?

Not at all	A little	A moderate amount	Very much	An extreme amount
------------	----------	-------------------	-----------	-------------------

4. How much do you need any medical treatment to function in your daily life?

Not at all	A little	A moderate amount	Very much	An extreme amount
------------	----------	-------------------	-----------	-------------------

5. How much do you enjoy life?

Not at all	A little	A moderate amount	Very much	An extreme amount
------------	----------	-------------------	-----------	-------------------

6. To what extent do you feel your life to be meaningful?

Not at all amount	A little	A moderate amount	Very much	An extreme
----------------------	----------	-------------------	-----------	------------

7. How well are you able to concentrate?

Not at all	A little	A moderate amount	Very much	Extremely
------------	----------	-------------------	-----------	-----------

8. How safe do you feel in your daily life?

Not at all	A little	A moderate amount	Very much	Extremely
------------	----------	-------------------	-----------	-----------

9. How healthy is your physical environment?

Not at all	A little	A moderate amount	Very much	Extremely
------------	----------	-------------------	-----------	-----------

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

10. Do you have enough energy for everyday life?

Not at all	A little	Moderately	Mostly	Completely
------------	----------	------------	--------	------------

11. Are your able to accept your bodily appearance?

Not at all	A little	Moderately	Mostly	Completely
------------	----------	------------	--------	------------

12. Have you enough money to meet your needs?

Not at all	A little	Moderately	Mostly	Completely
------------	----------	------------	--------	------------

13. How available to you is the information that you need in your day-to-day life?

Not at all	A little	Moderately	Mostly	Completely
------------	----------	------------	--------	------------

14. To what extent do you have the opportunity for leisure activities?

Not at all	A little	Moderately	Mostly	Completely
------------	----------	------------	--------	------------

15. How well are you able to get around?

Very poor	Poor	Neither poor no good	Good	Very good
-----------	------	----------------------	------	-----------

16. How satisfied are you with your sleep?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

17. How satisfied are you with your ability to perform your daily living activities?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

18. How satisfied are you with your capacity for work?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

19. How satisfied are you with yourself?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

20. How satisfied are you with your personal relationships?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

21. How satisfied are you with your sex life?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

22. How satisfied are you with the support you get from your friends?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

23. How satisfied are you with the conditions of your living place?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

24. How satisfied are you with your access to health services?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

25. How satisfied are you with your transport?

Very satisfied satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very
-----------------------------	--------------	---------------------------------------	-----------	------

The following question refers to how often you have felt or experienced certain things in the last four weeks.

26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

Never Seldom Quite often Very often Always

The Social Desirability Scale (SDSR-5) (Hays, Hayashi, & Stewart, 1989)

Listed below are a few statements about you in relationship to others.

Please indicate how much each statement is true or false for you on the answer sheet.

1. I am always courteous even to people who are disagreeable.

- (a) Definitely True
- (b) Mostly True
- (c) Don't Know
- (d) Mostly False
- (e) Definitely False

2. There have been occasions when I took advantage of someone.

- (a) Definitely True
- (b) Mostly True
- (c) Don't Know
- (d) Mostly False
- (e) Definitely False

3. I sometimes try to get even rather than forgive and forget.

- (a) Definitely True
- (b) Mostly True
- (c) Don't Know

- (d) Mostly False
- (e) Definitely False

4. I sometimes feel resentful when I don't get my way.

- (a) Definitely True
- (b) Mostly True
- (c) Don't Know
- (d) Mostly False
- (e) Definitely False

5. No matter who I'm talking to, I'm always a good listener.

- (a) Definitely True
- (b) Mostly True
- (c) Don't Know
- (d) Mostly False
- (e) Definitely False

Appendix BB: Information and consent sheet used in Chapter 6 questionnaire study

The Development of an Online Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain (CPP)

Participant Information Sheet (28/07/14, Version 3)

Researcher: Miznah Al-Abbadey

ERGO Study ID number: 11850

Please read this information carefully before deciding whether to take part in this research. You will need to indicate that you have understood this information before you can continue. You must also be female, aged 18 or over, and have experienced chronic pelvic pain for at least three months to participate. By ticking the box at the bottom of this page and clicking ‘Continue’, you are consenting to participate in this survey.

What is the research about?

The aim of the current study is to develop a new questionnaire to assess the impact of chronic pelvic pain on women’s lives. A new questionnaire will allow for more standardised comparisons between research studies. The questionnaire will be designed specifically for women with chronic pelvic pain and will assess factors considered relevant and important to them.

Why have I been chosen?

Women who have experienced chronic pelvic pain for at least three months are invited to take part. Participants are also required to be fluent in written English.

What will happen to me if I take part?

If you decide to take part, you will be directed to the online questionnaire, which will ask how your chronic pelvic pain has impacted your mood, work, socialising, personal relationships, and daily functioning. You will also be directed to other questionnaires, which will ask about your mood, wellbeing, quality of life, and relationships. On completion, you will be directed to a debrief page with a study overview and relevant contact details for further information/resources. The study should take approximately 20 minutes to complete.

Are there any benefits in my taking part?

There are no direct benefits to taking part. However, you will be contributing to research which aims to help women with chronic pelvic pain.

Are there any risks involved?

There are no major risks involved in this research. However, some items will ask personal questions, which can make some people feel uncomfortable and experience some negative emotions. All responses will be anonymous and you can withdraw from the study at any point without giving a reason, by closing down the webpage. Also, because the study requires participants to answer a series of questions online, you may risk experiencing eye and/or wrist strain. It is advised that you take a break from answering the questions if you feel any physical discomfort by getting up and moving away from the computer screen.

Will my participation be confidential?

Yes. The study complies with the Data Protection Act/University policy and the information will be stored and remain confidential. Data will be kept on a password-protected computer.

What happens if I change my mind?

If you change your mind you have the right to withdraw at any time without your legal rights being affected.

What happens if something goes wrong?

In the unlikely case of concern or complaint, please contact the chair of the Ethics Committee, Psychology, University of Southampton, SO17 1BJ, UK. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk.

Where can I get more information?

If you would like any more information about the study, please contact one of the research team members:

-Miznah Al-Abbaday (primary researcher) – maa1g10@soton.ac.uk

-Dr Cynthia Graham – c.a.graham@soton.ac.uk

-Dr Christina Lioffi – c.liossi@soton.ac.uk

☐ Please tick (check) this box to indicate that you consent to taking part in this survey

Appendix CC: Debrief sheet used in Chapter 6 questionnaire study

The Development of an Online Questionnaire that Assesses the Impact of Female Chronic Pelvic Pain (CPP)

Debriefing Statement (Version 2, 14/05/14, ERGO Number: 11850)

Thank you for taking part in this research. The aim of this research was to develop a new questionnaire to assess the impact of chronic pelvic pain (CPP) on women's lives. It is expected that a new CPP questionnaire will allow for more standardised comparisons between research studies. The information you provided will help assess the reliability and validity of the questionnaire. Once again, the results of this study will not include your name or any other identifying characteristics. The study did not use deception. You may have a copy of this summary and/or a summary of the research findings if you wish.

It is not uncommon to experience some anxieties or concerns when completing questionnaires about CPP and support is available. If participating in this study raised any issues for you, the following resources may be helpful:

- Pain UK – www.painuk.org
- Pelvic Pain Support Network - <http://www.pelvicpain.org.uk>
- Women's Health Concern - <http://www.womens-health-concern.org/>
- Vulvar Pain Society - <http://www.vulvalpainsociety.org/vps/>
- Endometriosis UK - <http://endometriosis-uk.org/>

If you have any further questions or concerns, you may also contact the research team members:

Miznah Al-Abbadey (primary researcher) – maalg10@soton.ac.uk

-Dr Cynthia Graham – c.a.graham@soton.ac.uk

-Dr Christina Liossi – c.liossi@soton.ac.uk

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, or would like to complain, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk

Appendix DD: Table 10 Demographic characteristics of participants in Chapter 6 questionnaire study

EFA participants ($N = 483$), CFA participants ($N = 484$), and overall dataset ($N = 969$)

Age:			
	EFA	CFA	Total Sample
Mean, (SD)	35.1 (11.92)	35.7 (12.0)	35.4 (11.96)
Range	18-76	18-78	18-78
Experience of pain (years):			
	EFA	CFA	Total Sample
Mean, (SD)	10.80 (8.67)	11.25 (9.28)	10.99 (8.98)
Range	0-56	0-50	0-56
Years since diagnosis:			
	EFA	CFA	Total Sample
Mean, (SD)	5.17 (6.0)	5.53 (6.67)	5.32 (6.31)
Range	0-45.08	0-40.00	0-45.08
Diagnoses (%):			
	EFA	CFA	Total Sample
Endometriosis	67.5	69.3	68.4
Vulvodynia	12.4	9.3	10.8
PCOS	13.9	12.1	13.0
Pelvic organ prolapse	3.3	3.5	3.4
Pelvic adhesions	26.1	21.6	23.8
IC	19.3	20.2	19.7
IBS	36.6	33.3	35.0
Pudendal neuralgia	2.3	2.1	2.2
Pelvic inflammatory disease	8.1	7.8	7.9
No diagnosis/unknown	11.2	9.3	10.2

Ethnic background (%):

	EFA	CFA	Total Sample
White	93.6	92.6	93.1
Mixed / multiple ethnic groups	2.7	2.5	2.6
Asian	1.2	1.6	1.4
Black/African/Caribbean	1.0	1.6	1.3
Other ethnic group	0.8	1.0	0.9

Country resident in (%):

	EFA	CFA	Total Sample
Europe	71.8	68	69.8
South America	0.4	0.4	0.3
Australia	1.2	1.9	1.5
Canada	1.0	1.9	1.4
East Asia	0.0	0.6	0.3
New Zealand	8.7	7.8	8.3
United States	16.6	18.5	17.5

Employment status (%):

	EFA	CFA	Total Sample
Homemaker	11.2	10.5	10.8
Paid full-time employment	40.6	49.0	44.8
Paid part-time employment	21.9	21.4	21.7
Retired	6.0	6.2	6.1
Unemployed	19	10.9	15.0

Student (%):

	EFA	CFA	Total Sample
Non-student	80.3	82.7	81.2
Full-time student	10.8	9.1	9.9

Part-time student	7.2	7.6	7.4
<hr/>			
Highest education level (%):			
	EFA	CFA	Total Sample
College or Equivalent	30.2	26.5	28.4
No qualifications	1.2	0.6	0.9
Other vocational/ work-related qualifications	4.3	4.9	4.6
Prefer not to say	0.8	0.8	0.8
Professional qualification	8.9	8.8	8.9
Secondary School/ High School	13.7	12.8	13.2
University Bachelor's degree or equivalent	25.3	27.0	26.1
University Postgraduate degree or equivalent	14.9	17.7	16.3
<hr/>			
Relationship status (%):			
	EFA	CFA	Total Sample
Casual relationship	1.9	1.6	1.8
Exclusive/committed relationship	76.8	77.4	77.1
Single	18.8	19.3	19.1
Marital status (%):			
	EFA	CFA	Total Sample
Divorced/separated	8.9	6.8	7.8
Civil partnership	3.9	3.9	3.9
Married	38.5	46.9	42.7
Single	46.2	40.3	43.2
Widowed	0.8	1.0	0.9

Note: "EFA" – Exploratory factor analysis; "CFA" – Confirmatory factor analysis

Appendix EE: Step by step guide of the decisions made resulting in the factor solutions

Factor analyses run using principle axis factoring and oblimin rotation						
Step Number	Ran FA1 / Action resulting from previous analysis	Result	Ran FA2 / Action resulting from previous analysis	Result	Ran FA3 / Action resulting from previous analysis	Result
1	Included all 52 items	Item 52 - No significant correlations with other items	Included all 52 items	12 Factors with eigen values >1 - explained 62.4% of the variance	Included all 52 items	12 Factors with eigen values >1 - explained 62.4% of the variance
		12 Factors with eigen values >1 - explained 62.4% of the variance		Item 52 - No significant correlations with other items		Item 52 - No significant correlations with other items
				Items that loaded strongly on more than one factor: 34		Items that loaded on a factor without theoretical sense: 45, 19
				Items that loaded on a factor without theoretical sense: 27, 45		Items that had no loadings on any factors: 52, 37
2	Included 51 items	11 factors retained - explained 61.48% of the variance	Removed items 52, 34, 27, 45	11 Factors with eigen values >1 - explained 58.61% of the variance	Removed items 52, 37, 19, 45	11 Factors with eigen values >1 - explained 61.79% of the variance
	removed item 52	Item 33 and 19 - hardly any significant	Included 48 items	Items that loaded strongly on more than one factor: 15	Included 48 items	Items that loaded on a factor without theoretical sense: 43

		correlations with other items				
	Specified 11 factors to be retained			Items that had no loadings on any factors: 51, 40		Items that had no loadings on any factors: 27, 4
3	Included 49 items	11 factors retained - explained 62.71% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15	10 Factors with eigen values >1 - explained 57.47% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4	10 Factors with eigen values >1 - explained 58.35% of the variance
	Removed items 52, 33, and 19	Items that loaded strongly on more than one factor: 10, 12, 45	Included 45 items	Items that loaded strongly on more than one factor: 11, 2	Included 45 items	Items that had no loadings on any factors: 3, 10
	Specified 11 factors to be retained	Items that that loaded on a factor without theoretical sense: 4, 10, 17, 30, 41, 47		Items that had no loadings on any factors: 37		Items that loaded on a factor without theoretical sense: 10
				Items that loaded on a factor without theoretical sense: 3		Items that loaded strongly on more than one factor: 10
4	Included 41 items	9 factors retained - explained 59.4% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 2, 3, 37	9 Factors with eigen values >1 - explained 55.95% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10	9 Factors with eigen values >1 - explained 57.26% of the variance
	Removed items 4, 10, 12, 17, 19, 30, 33, 41, 45, 47, 52	Items that loaded strongly on more than one factor: 49	Included 41 items	Items that loaded on a factor without theoretical sense: 43, 1, 7	Included 43 items	Items that loaded strongly on more than one factor: 2, 5

		Items that that loaded on a factor without theoretical sense: 3		Items that had no loadings on any factors: 6		
5	Included 39 items	9 factors retained - explained 60.53% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 2, 3, 37, 43, 1, 6, 7	8 Factors with eigen values >1 - explained 55.58% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10, 2, 5	8 Factors with eigen values >1 - explained 56.55% of the variance
	Removed items 3, 4, 10, 12, 17, 19, 30, 33, 41, 45, 47, 49, 52	Items that that loaded on a factor without theoretical sense: 5	Included 37 items	Items that loaded on a factor without theoretical sense: 19	Included 41 items	Items that loaded on a factor without theoretical sense: 17, 7, 1
				Items that loaded strongly on more than one factor: 30		Items that loaded strongly on more than one factor: 7, 1
						Items that had no loadings on any factors: 51
6	Included 38 items	9 factors retained - explained 61.03% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 2, 3, 37, 43, 1, 6, 7, 19, 30	7 Factors with eigen values >1 - explained 54.74% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10, 2, 5, 17, 7, 1, 51	7 Factors with eigen values >1 - explained 55.67% of the variance
	Removed items 3, 4, 5, 10, 12, 17, 19, 30, 33, 41, 45, 47, 49, 52	Items that correlated strongly on more than one factor: 34	Included 35 items	Items that loaded on a factor without theoretical sense: 17, 47, 25	Included 37 items	Items that loaded strongly on more than one factor: 47
		Items that that loaded on a factor without				Items that loaded on a factor without theoretical sense: 47, 29

		theoretical sense: 1, 6, 7, 11, 34				
						Items that had no loadings on any factors: 49
7	Included 33 items	8 factors retained - explained 60.21% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 2, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25	7 Factors with eigen values >1 - explained 54.49% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10, 2, 5, 17, 7, 1, 51, 47, 29, 49	6 Factors with eigen values >1 - explained 54.3% of the variance
	Removed items 1, 3, 4, 5, 6, 7, 10, 11, 12, 17, 19, 30, 33, 34, 41, 45, 47, 49, 52	Items that loaded strongly on more than one factor: 9	Included 32 items	Items that loaded on a factor without theoretical sense: 49	Included 34 items	Items that had no loadings on any factors: 48, 40
8	Included 32 items	8 factors retained - explained 60.40% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 2, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25, 49	6 Factors with eigen values >1 - explained 52.64% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10, 2, 5, 17, 7, 1, 51, 47, 29, 49, 48, 40	5 Factors with eigen values >1 - explained 53.7% of the variance
	Removed items 1, 3, 4, 5, 6, 7, 9, 10, 11, 12, 17, 19, 30, 33, 34, 41, 45, 47, 49, 52	Items that loaded strongly on more than one factor: 37	Included 31 items	Items that loaded on a factor without theoretical sense: 31	Included 32 items	Items that loaded strongly on more than one factor: 25
		Items that that loaded on a factor without		Items that had no loadings on any factors: 22		

		theoretical sense: 27, 29, 37				
9	Included 28 items	5 factors retained - explained 52.56% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 2, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25, 49, 22, 31	6 Factors with eigen values >1 - explained 53.30% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10, 2, 5, 17, 7, 1, 51, 47, 29, 49, 48, 40, 25	5 Factors with eigen values >1 - explained 53.49% of the variance
	Removed items 1, 3, 4, 5, 6, 7, 9, 10, 11, 12, 17, 19, 27, 29, 30, 33, 34, 37, 40, 41, 45, 47, 49, 52	Items that loaded strongly on more than one factor: 22	Included 29 items	Items that loaded strongly on more than one factor: 18	Included 31 items	Items that loaded on a factor without theoretical sense: 12, 30
10	Included 27 items	5 factors retained - explained 52.72% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 2, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25, 49, 22, 31, 18	6 Factors with eigen values >1 - explained 53.39% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10, 2, 5, 17, 7, 1, 51, 47, 29, 49, 48, 40, 25, 12, 30	5 Factors with eigen values >1 - explained 53.73% of the variance
	Removed items 1, 3, 4, 5, 6, 7, 9, 10, 11, 12, 17, 19, 22, 27, 29, 30, 33, 34, 37, 40, 41, 45, 47, 49, 52	Cronbach's alpha increases if removed item 2	Included 28 items	Items that loaded strongly on more than one factor: 12, 41	Included 29 items	Items that loaded on a factor without theoretical sense: 34

11	Included 26 items	5 factors retained - explained 53.50% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 2, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25, 49, 22, 31, 18, 12, 41	6 Factors with eigen values >1 - explained 53.53% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10, 2, 5, 17, 7, 1, 51, 47, 29, 49, 48, 40, 25, 12, 30, 34	5 Factors with eigen values >1 - explained 53.75% of the variance
	Removed items 1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 17, 19, 22, 27, 29, 30, 33, 34, 37, 40, 41, 45, 47, 49, 52	Items that loaded on a factor without theoretical sense: 25	Included 26 items		Included 28 items	Items that loaded on a factor without theoretical sense: 41
12	Included 25 items	5 factors retained - explained 53.28% of the variance	Removed items 52, 34, 27, 45, 51, 40, 15, 11, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25, 49, 22, 31, 18, 41	6 Factors with eigen values >1 - explained 53.00% of the variance	Removed items 52, 37, 19, 45, 43, 27, 4, 3, 10, 2, 5, 17, 7, 1, 51, 47, 29, 49, 48, 40, 25, 12, 30, 34, 41	5 Factors with eigen values >1 - explained 54.25% of the variance
	Removed items 1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 17, 19, 22, 25, 27, 29, 30, 33, 34, 37, 40, 41, 45, 47, 49, 52		Returned item 12 to see if it fits with factor 1 (functioning factor) and 2 to see if load s on one factor	Items that had no loadings on any factors: 20	Included 27 items	
			Included 28 items			

13			Removed items 52, 34, 27, 45, 51, 40, 15, 11, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25, 49, 22, 31, 18, 41, 20	6 Factors with eigen values >1 - explained 53.08% of the variance		
			Included 27 items	Items that loaded strongly on more than one factor: 4		
14			Removed items 52, 34, 27, 45, 51, 40, 15, 11, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25, 49, 22, 31, 18, 41, 20, 4	5 Factors with eigen values >1 - explained 51.44% of the variance		
			Included 26 items	Conducted Cronbach's alpha - alpha increased for work factor if remove item 2		
15			Removed items 52, 34, 27, 45, 51, 40, 15, 11, 3, 37, 43, 1, 6, 7, 19, 30, 17, 47, 25, 49, 22, 31, 18, 41, 20, 4, 2	5 Factors with eigen values >1 - explained 51.93% of the variance		
			Included 25 items			

Appendix FF: Table 11 showing summary of PAF rotated factor loadings for Model 1

25 items / Total variance explained: 62.54%

Factor 1: Emotional Impact

Eigenvalue: 8.09

% Variance: 32.34

Cronbach's α : .78

Factor loading / Items:

- .60 / (18) I have gotten upset easily because of my pain
 - .47 / (26) I experienced low mood because of the pain
 - .73 / (35) I have felt irritable or snappy because of the pain
 - .71 / (38) I felt angry because of the pain
 - .34 / (48) I felt concerned about the possibility of experiencing my pain for the rest of my life
 - .43 / (51) I felt unmotivated because of my pain
-

Factor 2: Sexual Impact

Eigenvalue: 3.36

% Variance: 13.46

Cronbach's α : .91

Factor loading / Items:

- .62 / (16) I avoided sexual activity because of the pain
- .66 / (21) Sexual activity has been very painful (either during or after sexual activity)
- .69 / (24) The pain has reduced my ability to feel sexually aroused (either during partnered sexual activity or during masturbation)
- .81 / (32) The pain has reduced my desire to engage in sexual activity
- .89 / (36) I have been unable to enjoy sexual activity because of the pain
- .68 / (42) I felt anxious about experiencing pain during sexual activity in future relationships
- .78 / (46) I felt guilty for not being able to engage in sexual activity because of the pain
- .83 / (50) I felt frustrated at not being able to engage in sexual activity

Factor 3: Relationship Impact

Eigenvalue: 1.17

% Variance: 6.88

Cronbach's α : .72

Factor loading / Items:

- .66 / (8) I have had difficulties communicating with my partner about my pain
- .58 / (14) I felt less connected to my partner because of the pain
- .74 / (39) My pain has not been taken seriously by my partner
- .48 / (43) I felt that I have been "heard" or listened to by people close to me when I have talked about the pain

Factor 4: Occupational Impact

Eigenvalue: 1.44

% Variance: 5.74

Cronbach's α : .76

Factor loading / Items:

- .74 / (23) I took time off work (including any voluntary work or education) because of the pain
- .55 / (28) I have felt negatively judged at work because of my pain
- .76 / (44) The pain has negatively affected my performance at work (including any voluntary work or education)

Factor 5: Psychological Impact

Eigenvalue: 1.03

% Variance: 4.12

Cronbach's α : .77

Factor loading / Items:

- .43 / (13) I felt unable to cope with my pain
- .49 / (15) I felt despair about my pain
- .40 / (20) I felt that my pain has taken over my life
- .37 / (31) I have had thoughts about ending my life because of the pain

Note: Numbers in parentheses "()" indicate the item number in the original questionnaire

Appendix GG: Table 12 showing summary of PAF rotated factor loadings for Model 2

25 items / Total variance explained: 61.58%

Factor 1: Emotional Impact

Eigenvalue: 1.42

% Variance: 5.69

Cronbach's α : .74

Factor loading / Items:

- .40 / (29) I felt negative about my body because of the pain
- .56 / (26) I experienced low mood because of the pain
- .67 / (35) I have felt irritable or snappy because of the pain
- .69 / (38) I felt angry because of the pain
- .35 / (48) I felt concerned about the possibility of experiencing my pain for the rest of my life

Factor 2: Sexual Impact

Eigenvalue: 7.87

% Variance: 31.46

Cronbach's α : .91

Factor loading / Items:

- .63 / (16) I avoided sexual activity because of the pain
- .70 / (21) Sexual activity has been very painful (either during or after sexual activity)
- .69 / (24) The pain has reduced my ability to feel sexually aroused (either during partnered sexual activity or during masturbation)
- .81 / (32) The pain has reduced my desire to engage in sexual activity
- .89 / (36) I have been unable to enjoy sexual activity because of the pain
- .65 / (42) I felt anxious about experiencing pain during sexual activity in future relationships
- .75 / (46) I felt guilty for not being able to engage in sexual activity because of the pain
- .82 / (50) I felt frustrated at not being able to engage in sexual activity

Factor 3: Relationship Impact

Eigenvalue: 1.80

% Variance: 7.20

Cronbach's α : .72

Factor loading / Items:

- .60 / (8) I have had difficulties communicating with my partner about my pain
- .49 / (14) I felt less connected to my partner because of the pain
- .65 / (39) My pain has not been taken seriously by my partner
- .68 / (33) I felt closer to my partner because of my pain

Factor 4: Occupational Impact**Eigenvalue:** 3.12**% Variance:** 12.47**Cronbach's α :** .76**Factor loading / Items:**

- .72 / (23) I took time off work (including any voluntary work or education) because of the pain
- .54 / (28) I have felt negatively judged at work because of my pain
- .77 / (44) The pain has negatively affected my performance at work (including any voluntary work or education)

Factor 5: General Functioning Impact**Eigenvalue:** 1.19**% Variance:** 4.76**Cronbach's α :** .79**Factor loading / Items:**

- .53 / (5) I found it difficult to sit because of the pain
- .50 / (9) I felt controlled by my pain
- .60 / (10) I had difficulties with wearing tight-fitting clothes because of the pain
- .41 / (12) Pain has stopped me from doing everyday activities that I would normally do (e.g. household jobs)
- .56 / (13) I felt unable to cope with my pain

Note: Numbers in parentheses “()” indicate the item number in the original questionnaire

Appendix HH: Table 13 showing summary of PAF rotated factor loadings for Model 3 (Superior model) / 27 items

Factor 1: Psychological Impact

Eigenvalue: 9.09

% Variance: 33.66

Cronbach's α : .84

Factor loading / Items:

- .55 / (6) I felt embarrassed about my pain
- .54 / (9) I felt controlled by my pain
- .67 / (11) I have felt socially isolated because of the pain
- .74 / (13) I felt unable to cope with my pain
- .57 / (15) I felt despair about my pain
- .46 / (20) I felt that my pain has taken over my life
- .50 / (22) The pain has made me feel less confident with myself
- .42 / (31) I have had thoughts about ending my life because of the pain

Factor 2: Sexual Impact

Eigenvalue: 3.39

% Variance: 12.56

Cronbach's α : .91

Factor loading / Items:

- .62 / (16) I avoided sexual activity because of the pain
- .70 / (21) Sexual activity has been very painful (either during or after sexual activity)
- .69 / (24) The pain has reduced my ability to feel sexually aroused (either during partnered sexual activity or during masturbation)
- .79 / (32) The pain has reduced my desire to engage in sexual activity
- .89 / (36) I have been unable to enjoy sexual activity because of the pain

- .63 / (42) I felt anxious about experiencing pain during sexual activity in future relationships
- .78 / (46) I felt guilty for not being able to engage in sexual activity because of the pain
- .82 / (50) I felt frustrated at not being able to engage in sexual activity

Factor 3: Relationship Impact

Eigenvalue: 1.84

% Variance: 6.82

Cronbach's α : .72

Factor loading / Items:

- .60 / (8) I have had difficulties communicating with my partner about my pain
- .52 / (14) I felt less connected to my partner because of the pain
- .66 / (39) My pain has not been taken seriously by my partner
- .63 / (33) I felt closer to my partner because of my pain

Factor 4: Occupational Impact

Eigenvalue: 1.49

% Variance: 5.51

Cronbach's α : .76

Factor loading / Items:

- .75 / (23) I took time off work (including any voluntary work or education) because of the pain
- .52 / (28) I have felt negatively judged at work because of my pain
- .77 / (44) The pain has negatively affected my performance at work (including any voluntary work or education)

Factor 5: Emotional Impact

Eigenvalue: 1.14

% Variance: 4.21

Cronbach's α : .75

Factor loading / Items:

.58 / (18) I have gotten upset easily because of my pain

.42 / (26) I experienced low mood because of the pain

.77 / (35) I have felt irritable or snappy because of the pain

.60 / (38) I felt angry because of the pain

Note: Numbers in parentheses “()” indicate the item number in the original questionnaire

Appendix II: Table 14 Goodness of fit indices for Models 2, 3, and the unidimensional model (N=462)

	χ^2 (df)	RMSEA	CFI
Unidimensional	3558.78 (324)**	0.15	0.51
Model 2	513.41 (258)**	0.05	0.95
Model 3	588.78 (300)**	0.05	0.96
Removal of item 42:	χ^2 (df)	RMSEA	CFI
Model 2	437.51 (235)**	0.04	0.96
Model 3	502.20 (274)**	0.04	0.97

Note: "***" - Significant at $p < .001$; Good fit is indicated by $CFI \geq .95$ and $RMSEA \leq .05$

Appendix JJ: Table 15 CFA regression weights for Model 2 (with item 42)

Loading	Estimate	S.E.	C.R.	P-Value	SRW
CPP48 <--- Emotion	1.000				.556
CPP38 <--- Emotion	1.864	.169	11.039	***	.751
CPP35 <--- Emotion	1.312	.138	9.517	***	.595
CPP26 <--- Emotion	1.695	.158	10.759	***	.719
CPP29 <--- Emotion	1.618	.157	10.334	***	.667
CPP50 <--- Sexual	1.000				.815
CPP46 <--- Sexual	1.048	.047	22.259	***	.798
CPP42 <--- Sexual	.234	.075	3.105	.002	.150
CPP36 <--- Sexual	1.014	.049	20.564	***	.838
CPP32 <--- Sexual	.847	.046	18.574	***	.776
CPP24 <--- Sexual	.920	.054	17.067	***	.771
CPP21 <--- Sexual	.900	.053	16.975	***	.725
CPP16 <--- Sexual	.872	.046	19.013	***	.790
CPP33 <--- Relation	1.000				.630
CPP39 <--- Relation	.870	.076	11.472	***	.558
CPP14 <--- Relation	1.610	.116	13.842	***	.907
CPP8 <--- Relation	1.361	.105	12.980	***	.747
CPP44 <--- Occupa	1.000				.797
CPP28 <--- Occupa	.999	.070	14.280	***	.717
CPP23 <--- Occupa	1.064	.070	15.194	***	.792
CPP13 <--- GenFunc	1.000				.800
CPP12 <--- GenFunc	.805	.054	14.935	***	.702
CPP10 <--- GenFunc	.549	.059	9.389	***	.458
CPP9 <--- GenFunc	.808	.048	16.754	***	.781
CPP5 <--- GenFunc	.559	.060	9.291	***	.460

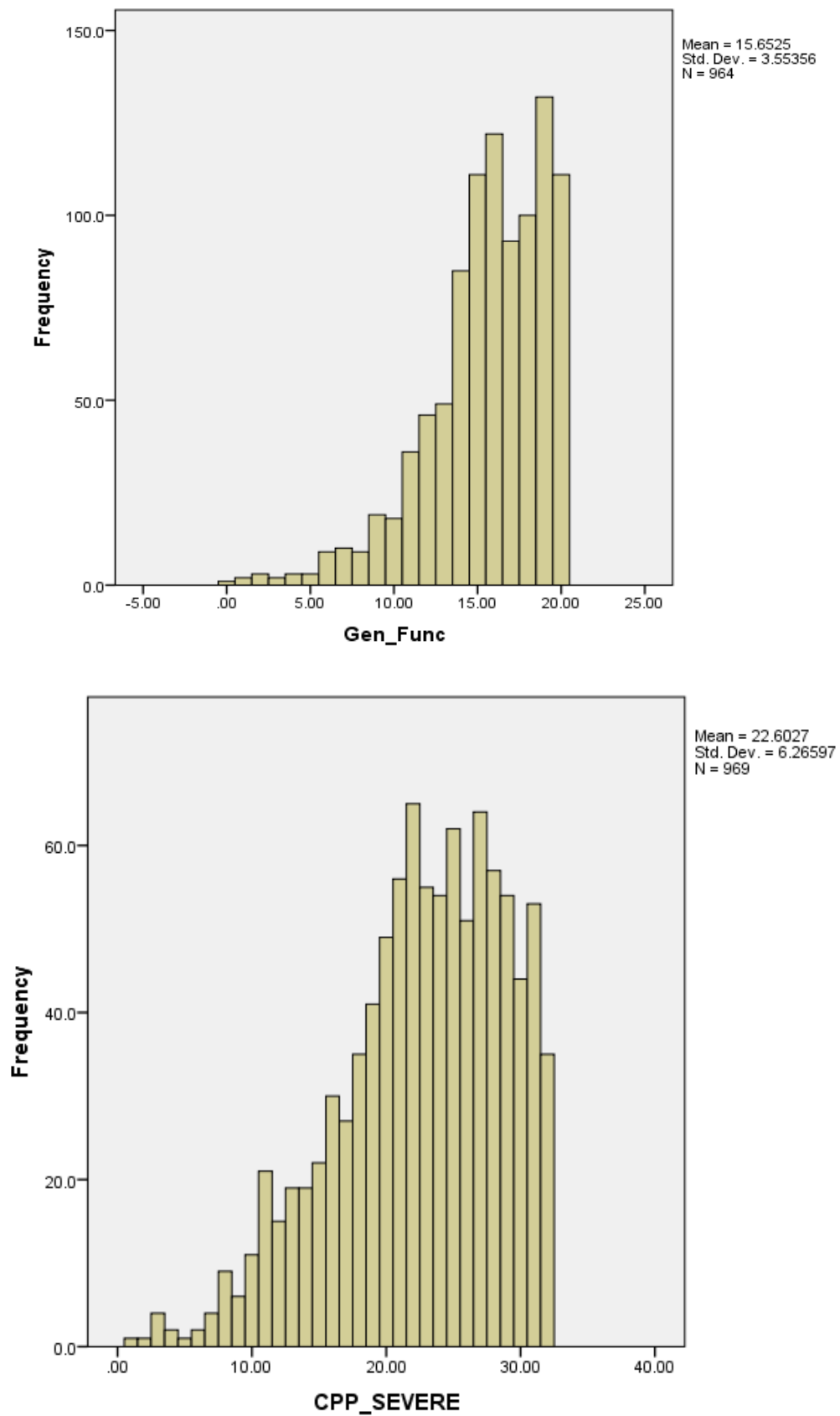
Note: “CPPxx” – Item from the IF-CPP; “S.E” – Standard error; “C.R” – Critical ratio; “***” – $P < .001$; “SRW” – Standardised regression weights.

Appendix KK: Table 16 CFA regression weights for Model 3 (with Item 42)

Loading	Estimate	S.E.	C.R.	P-Value	SRW
CPP38 <--- Emotion	1.000				.737
CPP35 <--- Emotion	.702	.062	11.285	***	.582
CPP26 <--- Emotion	.945	.065	14.616	***	.732
CPP18 <--- Emotion	.970	.063	15.394	***	.775
CPP50 <--- Sexual	1.000				.816
CPP46 <--- Sexual	1.050	.046	22.618	***	.802
CPP42 <--- Sexual	.240	.074	3.222	.001	.155
CPP36 <--- Sexual	1.014	.049	20.740	***	.842
CPP32 <--- Sexual	.837	.046	18.261	***	.768
CPP24 <--- Sexual	.905	.054	16.823	***	.761
CPP21 <--- Sexual	.900	.053	17.030	***	.726
CPP16 <--- Sexual	.863	.045	19.022	***	.789
CPP33 <--- Relation	1.000				.636
CPP39 <--- Relation	.756	.093	8.172	***	.492
CPP14 <--- Relation	1.582	.113	13.948	***	.904
CPP8 <--- Relation	1.335	.102	13.027	***	.742
CPP44 <--- Occupa	1.000				.792
CPP28 <--- Occupa	1.013	.072	14.168	***	.721
CPP23 <--- Occupa	1.065	.072	14.868	***	.783
CPP31 <--- Severe	1.000				.504
CPP22 <--- Severe	1.135	.112	10.164	***	.714
CPP20 <--- Severe	1.373	.122	11.292	***	.783
CPP15 <--- Severe	1.175	.113	10.374	***	.749
CPP13 <--- Severe	1.243	.119	10.425	***	.759
CPP11 <--- Severe	1.283	.121	10.620	***	.785
CPP9 <--- Severe	1.019	.103	9.928	***	.751
CPP6 <--- Severe	.969	.110	8.789	***	.552

Note: “CPPxx” – Item from the IF-CPP; “S.E” – Standard error; “C.R” – Critical ratio; “***” – $P < .001$; “SRW” – Standardised regression weights.

Appendix LL: Figure 4 Histograms showing the distribution of data for the fifth subscales from Models 2 and 3



Appendix MM: Table 17 Standardised and unstandardized regression weights of Model 3 (without item 42)

Loading	Estimate	S.E.	C.R.	P-Value	SRW
CPP38 <--- Emotion	1.000				.737
CPP35 <--- Emotion	.703	.062	11.246	***	.582
CPP26 <--- Emotion	.945	.065	14.567	***	.733
CPP18 <--- Emotion	.969	.063	15.321	***	.774
CPP50 <--- Sexual	1.000				.815
CPP46 <--- Sexual	1.052	.047	22.609	***	.803
CPP36 <--- Sexual	1.014	.049	20.706	***	.842
CPP32 <--- Sexual	.837	.046	18.196	***	.767
CPP24 <--- Sexual	.906	.054	16.818	***	.761
CPP21 <--- Sexual	.900	.053	16.991	***	.725
CPP16 <--- Sexual	.864	.045	19.020	***	.790
CPP33 <--- Relation	1.000				.637
CPP39 <--- Relation	.755	.092	8.173	***	.491
CPP14 <--- Relation	1.582	.113	13.960	***	.904
CPP8 <--- Relation	1.334	.102	13.031	***	.742
CPP44 <--- Occupa	1.000				.792
CPP28 <--- Occupa	1.014	.071	14.185	***	.722
CPP23 <--- Occupa	1.064	.071	14.884	***	.783
CPP31 <--- Severe	1.000				.505
CPP22 <--- Severe	1.146	.112	10.218	***	.723
CPP20 <--- Severe	1.377	.122	11.317	***	.787
CPP15 <--- Severe	1.138	.111	10.203	***	.727
CPP13 <--- Severe	1.224	.118	10.357	***	.748
CPP11 <--- Severe	1.291	.121	10.657	***	.792

CPP9 <--- Severe	.988	.101	9.800	***	.730
CPP6 <--- Severe	.973	.110	8.818	***	.555

Note: “CPPxx” – Item from the IF-CPP; “S.E” – Standard error; “C.R” – Critical ratio; “***” – $P < .001$; “SRW” – Standardised regression weights.

Appendix NN: Table 18 Standardised and unstandardized regression weights of Model 2 (without item 42)

Loading	Estimate	S.E.	C.R.	P-Value	SRW
CPP48 <--- Emotion	1.000				.556
CPP38 <--- Emotion	1.863	.169	11.038	***	.751
CPP35 <--- Emotion	1.312	.138	9.518	***	.595
CPP26 <--- Emotion	1.695	.158	10.760	***	.719
CPP29 <--- Emotion	1.618	.157	10.333	***	.667
CPP50 <--- Sexual	1.000				.814
CPP46 <--- Sexual	1.050	.047	22.249	***	.799
CPP36 <--- Sexual	1.015	.049	20.529	***	.838
CPP32 <--- Sexual	.846	.046	18.512	***	.775
CPP24 <--- Sexual	.922	.054	17.067	***	.772
CPP21 <--- Sexual	.900	.053	16.942	***	.724
CPP16 <--- Sexual	.874	.046	19.005	***	.791
CPP33 <--- Relation	1.000				.630
CPP39 <--- Relation	.870	.076	11.470	***	.558
CPP14 <--- Relation	1.610	.116	13.848	***	.907
CPP8 <--- Relation	1.360	.105	12.978	***	.747
CPP44 <--- Occupa	1.000				.797
CPP28 <--- Occupa	.999	.070	14.279	***	.717
CPP23 <--- Occupa	1.064	.070	15.193	***	.792
CPP13 <--- GenFunc	1.000				.800
CPP12 <--- GenFunc	.805	.054	14.936	***	.702
CPP10 <--- GenFunc	.549	.059	9.389	***	.458
CPP9 <--- GenFunc	.808	.048	16.754	***	.781
CPP5 <--- GenFunc	.559	.060	9.291	***	.460

Note: “CPPxx” – Item from the IF-CPP; “S.E” – Standard error; “C.R” – Critical ratio; “***” – $P < .001$; “SRW” – Standardised regression weights.

Appendix OO: Table 19 Correlations between factors in Model 3

	1	2	3	4	5
Emotion	-				
Sexual	.330	-			
Relationship	.357	.671	-		
Occupation	.466	.157	.105	-	
Psych	.873	.398	.369	.52	-

Appendix PP: Table 20 Cronbach's alphas of the validated measuresQuestionnaire α

HADS-A	0.79
HADS-D	0.84
DSC	0.90
FSDS-R	0.95
PDI	0.89
WHO-PHYS	0.85
WHO-PSYCH	0.84
WHO-SOCIAL	0.61
WHO-ENVIR	0.81
SDRS	0.65

Note: "HADS-A" - The Hospital Anxiety and Depression Scale – Anxiety scale; "HADS-D" - The Hospital Anxiety and Depression Scale – Depression scale; "DSC" - The Dyadic Sexual Communications Scale; "FSDS-R" - The Female Sexual Distress Scale – Revised; "PDI" - The Pain Disability Index; "WHO_PHYS" – The WHO quality of life-Bref physical health subscale; "WHO_PSYCH" - The WHO quality of life-Bref psychological health subscale; "WHO_SOCIAL" - The WHO quality of life-Bref social subscale; "WHO_ENVIR" - The WHO quality of life-Bref environment subscale; "SDRS" – Social Desirability Response Set.

Appendix QQ: Table 21 Pearson correlations between the IF-CPPQ subscales and total score with validated measures

Factor	Questionnaire	Expected correlation direction	r Value	r ²
Emotional Impact	HADS-A	Positive	0.49**	0.24
	HADS-D	Positive	0.44**	0.19
	WHO_PSYCH	Negative	-0.46**	0.21
	SDRS-5	Positive	0.048	0.002
Sexual Impact	DSC	Negative	-0.18**	0.03
	FSDS-R	Positive	0.6**	0.36
	SDRS-5	Positive	0.049	0.002
Relationship Impact	DSC	Negative	-0.4**	0.16
	FSDR-R	Positive	0.39**	0.15
	WHO_SOCIAL	Negative	-0.45**	0.20
	SDRS-5	Positive	0.035	0.001
Occupational Impact	PDI	Positive	0.47**	0.22
	WHO_PHYS	Negative	-0.5**	0.25
	SDRS-5	Positive	0.072	0.005
Psychological Impact	HADS-A	Positive	0.5**	0.25
	HADS-D	Positive	0.59**	0.35
	WHO_PSYCH	Negative	-0.6**	0.36
	SDRS-5	Positive	0.123**	0.015
IF-CPP Tot	WHO-1	Negative	-0.37**	0.14
	WHO-2	Negative	-0.38**	0.14
	PDI	Positive	0.44**	0.19
	SDRS-5	Positive	0.075	0.006

Note: “HADS-A” - The Hospital Anxiety and Depression Scale – Anxiety scale; “HADS-D” - The Hospital Anxiety and Depression Scale – Depression scale; “DSC” - The Dyadic Sexual Communications Scale; “FSDS-R” - The Female Sexual Distress Scale – Revised; “PDI” - The Pain Disability Index; “WHO_PHYS” – The WHO quality of life-Bref physical health subscale; “WHO_PSYCH” - The WHO quality of life-Bref psychological health subscale; “WHO_SOCIAL” - The WHO quality of life-Bref social health subscale; “WHO-1” - The WHO quality of life-Bref overall quality of life; “WHO-2” - The WHO quality of life-Bref overall health; “SDRS-5” – The Social Desirability Response Set-5; “**” – $p < 0.001$.

Appendix RR: Final 26 item IF-CPPQ

This questionnaire is intended to be used by adult women who experience chronic pelvic pain. The questionnaire aims to assess the impact of chronic pelvic pain on women's lives in terms of everyday activities (e.g. being able to sit, household tasks, and hobbies), being able to work, socialising, relationships, and sexual relationships.

Thinking about the past month only, please indicate how much you agree or disagree with the following statements. The questions concern your chronic pelvic pain. Please answer each question with respect to your chronic pelvic pain.

Answer format:

Response categories:	Scoring:
Strongly disagree	0
Disagree	1
Neither agree nor disagree	2
Agree	3
Strongly agree	4

- 1) I felt embarrassed about my pain
- 2) I have had difficulties communicating with my partner about my pain*
- 3) I felt controlled by my pain
- 4) I have felt socially isolated because of the pain
- 5) I felt unable to cope with my pain
- 6) I felt less connected to my partner because of the pain*
- 7) I felt despair about my pain
- 8) I have avoided sexual activity because of the pain*
- 9) I have gotten upset easily because of the pain
- 10) I felt that my pain has taken away my life
- 11) Sexual activity has been very painful (either during or after sexual activity)*
- 12) The pain has made me feel less confident
- 13) I took time off work (including any voluntary work or education) because of the pain*

- 14) The pain has reduced my ability to feel sexually aroused (either during partnered sexual activity or during masturbation)*
- 15) I experienced low mood because of the pain
- 16) I have felt negatively judged at work because of my pain*
- 17) I have had thoughts about ending my life because of the pain
- 18) The pain has reduced my desire to engage in sexual activity*
- 19) I felt closer to my partner because of my pain*
- 20) I felt irritable or snappy because of the pain
- 21) I have been unable to enjoy sexual activity because of the pain*
- 22) I felt angry because of the pain
- 23) My pain has not been taken seriously by my partner*
- 24) The pain has negatively affected my performance at work (including any voluntary work or education)*
- 25) I felt guilty for not being able to engage in sexual activity because of the pain*
- 26) I felt frustrated at not being able to engage in sexual activity*

*indicates that these questions will have an additional response option – “Not applicable”

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