Towards an Understanding of Men's Experiences of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)

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ABSTRACT

Chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) is a chronic pain condition that can affect men of any age, and has an estimated prevalence of up to 16% (Mehik, Hellström, Lukkarinen, Sarpola, & Järvelin, 2000). Aetiology is currently unknown, and it is a highly heterogeneous condition characterised by persistent pain in the pelvic region, urinary difficulties, and sexual dysfunction. Current literature indicates that it pervades many aspects of men's lives, and is associated with a significantly impaired quality of life, comparable to other long-term conditions such as Crohn's disease, diabetes mellitus, and congestive heart failure (McNaughton Collins et al., 2001; Wenninger, Heiman, Rothman, Berghuis, & Berger, 1996). Despite this, extremely few studies have explored men's experiences of living with CP/CPPS.

This study aimed to increase understanding of men's experiences of living with CP/CPPS, with a particular consideration of how they influence and are influenced by social contexts and relationships. A qualitative approach was adopted, and data from 8 semi-structured interviews was analysed using thematic analysis. All participants were based in the UK and had a diagnosis of CP/CPPS. Duration of illness within the sample ranged from 3 to 43 years.

Three overarching themes were constructed: 'trying to make sense of what is "wrong" in "a spiral of confusion,"' 'managing day-to-day with an illness that is debilitating and unpredictable,' and 'sociality and isolation.' Similar to other studies, it was found that participants often experienced CP/CPPS as an overwhelming and frightening illness, which could challenge day-to-day life, and the assumptions men held about themselves. Relationships and social contexts were found to be important contexts in which participants sought support and made sense of what it meant to live with CP/CPPS. A number of clinical and research implications are discussed, highlighting that there is much more that can be done to alleviate suffering for men affected by CP/CPPS.

CONTENTS

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1. INTRODUCTION

This chapter reviews literature that explores men's experiences of living with chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS). It then defines and justifies the rationale and aims of this study. To provide sufficient context, a brief overview of chronic pain, and current diagnostic and treatment processes for CP/CPPS are provided. Towards the end of the chapter, relevant theories and models for understanding chronic illness are also discussed.

1.1. What is Chronic Pain?

The definition of chronic pain is contingent on the definition of pain, which is described by the International Association for the Study of Pain (IASP) as:

> "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (p. 210).

Pain is considered *chronic* when it persists beyond typical healing time, with 3 months often used as a convenient threshold (IASP, 1994). Recent estimates have found that 43% of the UK adult population (amounting to just under 28 million people) experience chronic pain, and that 14.2% experience chronic pain as moderately or severely limiting day-to-day activity (Fayaz, Croft, Langford, Donaldson, & Jones, 2016).

Chronic pain is associated with an impaired quality of life (QoL), as well as an increased risk of anxiety, depression and suicidality (Azevedo, Costa-Pereira, Mendonça, Dias, & Castro-Lopes, 2012; Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Racine, 2018). Furthermore, chronic pain is a condition mired by a lack of medically accepted understanding, which has been found to leave sufferers struggling to construct pain as credible (Toye, Seers, & Barker, 2017; Toye, Seers, Hannink, & Barker, 2017).

Chronic *pelvic* pain (CPP) refers to persistent pain in structures related to the pelvis (Engeler et al., 2020). It is an area of chronic pain that is relatively neglected (Toye, Seers, & Barker, 2014). In particular, it has been argued that CPP has suffered from a sparsity of studies that explore subjective experiences, which has hampered interventions that consider biological, psychological, and social factors in an integrated and equitable way (Grace, 2000). Although CPP can be experienced by men and women, research is largely separated by gender, with significantly more studies exploring the experiences of women than men (Toye et al., 2014). This is clearly demonstrated in a meta-ethnography of qualitative literature conducted by Toye et al. (2014), in which the authors found 30 studies relating to women's experiences, and only two studies relating to men's experiences. It is therefore unsurprising that there have been multiple calls by researchers, clinicians, and sufferers for more research (Hatchett et al., 2009; Toye et al., 2014; Wood, Qureshi, & Mughal, 2017).

1.2. What is CP/CPPS?

CPP in men is frequently identified using the diagnostic term CP/CPPS. This accounts not only for persistent pain in the pelvic region (including perineum, pelvis, testicles, penis, rectum, prostate, and abdomen), but also concomitant difficulties relating to urination (such as painful urination, urgency, trouble voiding), and/or sexual dysfunction (such as painful or premature ejaculation, erectile dysfunction, loss of libido) (Harvard Medical School, 2019; Krieger, Nyberg, & Nickel, 1999; Pirola, Verdacchi, Rosadi, Annino, & De Angelis, 2019). Aetiology is currently unknown, and it is a highly heterogeneous condition which means symptoms and symptom severity varies between sufferers (DeWitt-Foy, Nickel, & Shoskes, 2019; Reichard, Makovey, & Shoskes, 2015; Tripp & Nickel, 2013).

The National Institute of Health (NIH) currently classifies CP/CPPS as a sub-category of prostatitis (Krieger et al., 1999).

- Category I: Acute bacterial prostatitis (ABP)
- Category II: Chronic bacterial prostatitis (CBP)
- Category III: Chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS)
- Category IV: Asymptomatic inflammatory prostatitis (AIP)

CP/CPPS (category III) is both the least understood, and most common category of prostatitis, with evidence suggesting it accounts for 90-95% of cases (De La Rosette, Hubregtse, Meuleman, Stolk-Engelaar, & Debruyne, 1993; Tripp & Nickel, 2013). Under this classification system the NIH describes CP/CPPS as the “presence of genitourinary pain in the absence of uropathogenic bacteria” (p. 236).

There is criticism of CP/CPPS’s classification as a subcategory of prostatitis, as well as the persistence of the term prostatitis, on the basis that CP/CPPS is distinct from other categories due to the *absence* of identifiable infection, and because pain can be experienced in organs and muscles other than the prostate (Tripp & Nickel, 2013). CP/CPPS is also widely recognised as a chronic pain condition (Rees & Cooper, 2015; Turner, Ciol, Korff, Liu, & Berger, 2006). The European Association of Urology (EAU) for example, who are influential in providing clinical guidance for supporting CPP and urological diseases, have opted to use the term CPPS alone, arguing that the term prostatitis should be avoided as it misleadingly implicates the prostate, and infectious pathology (Engeler et al., 2020). Using the term CPPS also dissolves the inherent division of gender.

This debate, and the variation in terminology, arguably reflects a diversity of views, and a lack of shared understanding within the current research and healthcare community. At present, there are multiple theories pertaining to mechanisms that may be involved (Adamian et al., 2020; C. Smith, 2016). This includes theories relating to neurotransmitters, pelvic floor dysfunction, anatomical anomalies, malignancy, psychological and behavioural triggers, inflammation and autoimmunity, infection, and gut microbiome (Adamian et al., 2020). However, evidence remains inconclusive, providing little insight into what CP/CPPS means for those who suffer with it, nor guiding effective treatment.

The diversity of views and lack of understanding has unsurprisingly been found to be replicated in online resources aimed at supporting sufferers. Showghi and Williams (2012) identified and reviewed 23 accessible websites (in the UK) looking at the quality of content. They concluded that there was a wide variety of nomenclature, divergent explanations, outdated and unclear evidence and authorship, and that this was likely to cause confusion and distress to sufferers of CP/CPPS. They did not however explore how this was experienced by sufferers.

1.2.1. Prevalence

CP/CPPS affects a relatively high number of men, accounting for up to 13.8% of visits to outpatient urology appointments (Bartoletti et al., 2007; McNaughton Collins et al., 2002). And overall prevalence has been estimated between 2.2-16% (Krieger et al., 2008; Mehik et al., 2000; Nickel, Downey, Hunter, & Clark, 2001; Roberts et al., 1998).

Unlike other prostate-related illnesses, such as prostate cancer or benign prostatic hyperplasia, CP/CPPS has been found to effect men of all ages with no evidence that incidence of diagnosis increases with age (Nickel et al., 2001; Tripp, Nickel, Ross, Mullins, & Stechyson, 2009). In fact in a study in the US it was reported that prostatitis was more frequently diagnosed in men between the ages of 36–65 than in men aged over 66 years (McNaughton Collins, Stafford, O'Leary, & Barry, 1998). And in another study 'chronic prostatitis-like symptoms' were also found to be more prevalent in men younger than 50, than older than 50, although the difference was not significant (Nickel et al., 2001). It has also been found to have an estimated prevalence of 8.3% in an adolescent population in Canada, further highlighting that age is not a risk factor (Tripp et al., 2009).

CP/CPPS has also been found to affect men across the world, although research has been criticised for failing to consider ethnicity (Tripp et al., 2006). One study analysed 58,995 visits to physicians in the US for prostatitis and found that frequency of diagnosis did not vary significantly between White and Black Americans (McNaughton Collins et al., 1998). And in another study, in which 3147 men participated in a survey in Malaysia, it was reported prevalence of CP/CPPS ranged from 8% in Malay men, 8.9% in Indian and Chinese men, and 16% in other ethnic groups (which were not specifically disclosed) (Cheah et al., 2003).

1.3. Diagnostic Process and Treatment

1.3.1. Diagnostic Process

EAU guidelines advise that initial assessment of CPP should include a comprehensive history taking, and a physical examination (Engeler et al., 2020). As there are no diagnostic tests which can confirm the presence of CP/CPPS, clinicians are required to follow a process of excluding evidence of infection, inflammation, or other pathology (Engeler et al., 2020; Rees & Cooper, 2015). Authors of the EAU guidelines have reflected that the process of diagnosis often produces a dilemma for clinicians: balancing the exploration of treatable disease, whilst introducing the idea of chronic and life-threatening illnesses, which can provoke feelings of anxiety in the patient (Engeler et al., 2020).

Currently there are two clinical tools used to support the evaluation and diagnosis of CP/CPPS in clinical settings: the NIH-Chronic Prostatitis Symptoms Index (NIH-CPSI) questionnaire, and the ‘UPOINT’ classification system. Both tools aim to capture the collection of symptoms, and the impact of CP/CPPS on an individual’s life. The NIH-CPSI includes nine questions investigating pain, urinary symptoms, and QoL. It is based on self-reporting, and includes a measure of severity of pain to be rated using a Likert scale, from 0 (no pain) to 10 (pain as bad as you can imagine) (Litwin et al., 1999). It has been found to be responsive to change, so can be used for monitoring illness over time. However it has also been criticised for overlooking sexual dysfunction, and providing a crude measure of QoL (S. Davis, Binik, & Carrier, 2009; Propert et al., 2006).

The UPOINT classification system developed by Shoskes et al. (2009) considers:

- Urinary symptoms;
- Psychosocial dysfunction (depression or catastrophising thoughts);
- Organ-specific findings (e.g. prostate tenderness, swelling)
- Infection (exclusion of infection);
- Neurological/systemic (presence of other pain conditions);
- Tenderness of muscles (presence of muscle spasm or trigger points).

Unlike the NIH-CPSI it is not a series of closed-questions, but a framework for the appraisal of factors which may be implicated. It has been argued that this helps to define an individualised and multimodal approach to interventions (Doiron, Tripp, Tolls, & Nickel, 2018; Piontek et al., 2019; Pirola et al., 2019; J. Zhang, Liang, Shang, & Li, 2020). This tool has however received criticism for overlooking sexual dysfunction, and for limiting the psychosocial domain to depression, and catastrophising thoughts (Magri et al., 2010; Riegel et al., 2014).

1.3.2. Treatment

No definitive cure exists for CP/CPPS, and therefore current treatment is focused on long-term symptom management. This can include a variety of interventions including medication (anti-inflammatories, neuromodulators, alpha-inhibitors, antidepressants, antibiotics), physiotherapy, surgery, acupuncture, extracorporeal shock wave therapy, and psychological therapy (Adamian et al., 2020; Doiron, Shoskes, & Nickel, 2019; Pirola et al., 2019; J. Zhang et al., 2020). It is argued that interventions should target reduction in symptoms and improved QoL, and be tailored to the patient's specific presentation (DeWitt-Foy et al., 2019; Magistro et al., 2016).

Historically sufferers have been treated within a biomedical model, which is likely to have utilised pharmacological interventions (Nickel, Baranowski, Pontari, Berger, & Tripp, 2007). However, research has shown that there is little effectiveness in any one pharmacological intervention, and mono-therapeutic treatment is not recommended (Engeler et al., 2020; Magistro et al., 2016). Pharmacological interventions can also result in side effects such as hypotension, dizziness and ejaculatory dysfunction (Franco, Tirapegui, Garrote, & Vietto, 2018). Despite this, there is evidence that men continue to be primarily offered pharmacological interventions, including antibiotics even though there is no proven bacterial cause (Turner et al., 2006).

Increasingly research supports the use of UPOINT to guide a multimodal approach (Adamian et al., 2020; Doiron et al., 2019; Guan et al., 2015; Magistro et al., 2016; Shoskes, Nickel, & Kattan, 2010; J. Zhang et al., 2020). This is also endorsed by current guidelines published by EAU (Engeler et al., 2020), Prostate Cancer UK (Rees, Abrahams, Doble, & Cooper, 2014), and National Institute for Clinical Excellence (2019), who recommend that multimodal interventions are supported by multi-disciplinary teams (i.e. urologists, pain specialists, psychologists, physiotherapists, nurses), with an emphasis on patient involvement, and self-management skills.

1.3.2.1. Psychological Interventions

Only two studies were found to have explored the effectiveness of psychological interventions for men with CP/CPPS, even though psychological support is advised (Nickel, Mullins, & Tripp, 2008; Tripp, Nickel, & Katz, 2011). One evaluated the feasibility of an 8 week cognitive-behaviour program developed specifically for men with CP/CPPS. Using psychometric questionnaires (short-form McGill Pain Questionnaire, Pain Catastrophising Scale, Multidimensional Scale of Perceived Social Support, Centre for Epidemiological Studies Depression Scale, and NIH-CPSI), Tripp, Nickel & Katz

(2011) found significant reductions in pain, disability, catastrophising cognitions, and improvement in QoL. There were however no changes in depressive symptoms or social support. The authors reflected that the program encouraged men to take an active role in their treatment, fostering a sense of hope that they could manage their own symptoms.

Another study evaluated the effectiveness of a 7 week programme which integrated aspects of mindfulness, cognitive behavioural therapy (CBT), and Sensate Focus, with an emphasis on improving sexual relationships (Edwards et al., 2019).[1] The main parts of this programme were myth busting and pain education, exploring sensations and feelings, and engaging in experimentation, that aligned with a self-developed model called ‘ReConnect’. The authors reported the model was developed within a chronic pain service in the UK, in response to a high prevalence of intimacy concerns from men (and women) with CPP. They measured effectiveness using the anxiety subscale of the Multidimensional Sexuality Questionnaire. Results show that for the 55 men who participated, there was a non-significant reduction in anxiety about sexual activity post treatment.

These results suggest that psychosocial interventions can be effective, however it is difficult to make generalisations based on two studies. In the field of chronic pain more generally, research into the efficacy of psychological interventions suggest that cognitive and behavioural approaches, including third-wave therapies such as acceptance and commitment therapy (ACT), and mindfulness, have been found to be beneficial (McCracken & Vowles, 2014; Morley & Williams, 2015). However, it is currently unclear how much this would be helpful to men with CP/CPPS given the lack of research that explores their experiences of CP/CPPS.

1.4. Men’s Experiences of CP/CPPS

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[1] Sensate Focus is a psychosexual therapy aimed at building confidence in intimacy

Research has consistently found that men with CP/CPPS experience impaired QoL (Piontek et al., 2019; Riegel et al., 2014; Zhao et al., 2010). The following section will provide a detailed overview of available literature that has specifically considered men's experiences of living with CP/CPPS. Based on the review, it was found that the vast majority of studies utilised psychometric measures to explore men's experiences, which have been criticised for underestimating and underrepresenting lived experiences (Riegel et al., 2014). Only three studies to date were found to have used qualitative methodology (Hatchett et al., 2009; Jonsson & Hedelin, 2008; Wood et al., 2017). One of which included a mixed sample of 23 men (with CP/CPPS), and 24 women (with painful bladder syndrome/interstitial cystitis) (Hatchett et al., 2009). Given the sparsity of qualitative literature it was decided to include it in this review.

The literature is organised by common themes, and the methodologies that studies employed are detailed, to help clearly differentiate.

1.4.1. Quality of Life

Quantitative studies have used psychometric measures to consider overall 'QoL', however there is some variation in the definitions and tools used to capture this. For example, Zhao et al. (2010) explored health-related QoL using the instruments EuroQol, which includes dimensions of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression; and the Short Form-6D, which includes dimensions of physical functioning, role-limitations, social functioning, pain, mental functioning, and vitality. Compared with the general population they found that men with CP/CPPS had significantly reduced health-related QoL, and that pain severity (but not urinary symptoms, or symptom duration) was the main predictor of impaired health-related QoL.

Sociodemographic and comorbidities were not found to significantly contribute towards QoL, however when age groups were matched, significant differences were present only in the younger age range (20-49), suggesting that age may be important (Zhao et al., 2010). This is similar to a study by Piontek et al.

(2019), who had a mixed sample with diagnosis of CPPS (103 men and 131 women). Using the Short Form-12 to measure mental and physical QoL, they found that increasing age was significantly associated with increased mental QoL, explaining 7% of the variance. They also found that younger age was significantly associated with increased physical QoL. Age (and sex) were not found to have any significant relationship with symptoms severity, indicating that factors beyond symptom severity may be influential in QoL.

Impaired QoL has also been found to be consistent over time, and across men and their partners. Tripp et al (2013) monitored a sample of 44 men and their spouses over a 2 year period, using a range of health-related QoL measures, and found that QoL did not significantly differ between men and their spouses, and that over time physical QoL increased whilst mental QoL decreased (Tripp, Nickel, & Shoskes, 2013).

1.4.2. Anxiety

Research suggests that men with CP/CPPS experience an increased level of anxiety, with a significant (albeit varied) proportion reaching clinical cut-offs for anxiety disorders, across a number of psychometric measures. For example, in a sample of 80 men in China, 62.3% met clinical cut-off according to the Hospital and Anxiety Depression Scale, compared to only 15% of the control group (G. Zhang, Bai, Xu, & Wang, 2011). They also found men younger than 35 years were associated with relatively higher anxiety scores than men aged over 35 years (G. Zhang et al., 2011). Whereas in another study, with a sample of 71 men, using the Generalised-Anxiety Disorder scale, it was found that 22.45% met the cut-off for an anxiety disorder (Brünahl et al., 2017). This was not however compared with a control group. Overall, this gives an indication that anxiety is often heightened in men with CP/CPPS, however as cross-sectional studies, they provide little insight into factors that may be contributing towards and interacting with heightened feelings of anxiety.

In a longitudinal study looking at anxiety in men and their spouses, it was found that anxiety remained stable across a 2 year period for both men and their spouses, however spouses reported lower levels of anxiety whilst men’s level of anxiety remained elevated (Tripp et al., 2013). Information regarding interventions during this period of time were however not collected so it is again unclear what might (or might not) contribute towards changes in anxiety but suggests that it can be maintained at a heightened level over time.

In a large-scale population-based dataset (8,088 men with CP/CPPS and 24,264 randomly matched controls), anxiety has also been found to be a risk factor in the development of CP/CPPS (Chung & Lin, 2013). In this study it was found that men with CP/CPPS are 2.1 times more likely to have had a prior diagnosis of an anxiety disorder (11.5% compared to 5.7% in a control group) (Chung & Lin, 2013). The underlying mechanisms remain unclear and there are no similar studies to compare with, however Chung and Lin (2013) put forward a hypothesis that stress and anxiety may influence the hypothalamic-pituitary-adrenal axis, which in turn has been shown to lead to abnormal inflammatory responses causing physiological change. The relationship between stress responses, and physiological change is also suggested in other studies, however this remains an association as data cannot currently support causal inferences (Anderson, Orenberg, Morey, Chavez, & Chan, 2009; Ullrich, Turner, Ciol, & Berger, 2005).

Qualitative studies provide more insight into how anxiety is experienced by men with CP/CPPS. Jonsson and Hedelin (2008), carried out interpretive phenomenological analysis (IPA) on data from semi-structured interviews with 10 men with CP/CPPS in Sweden. They reported that participants worried symptoms were malignant (e.g. prostate cancer) and that this had not been identified. They also reported anxiety about ‘losing control’ of their bodies which they found related to the unpredictable pattern to the way in which symptoms flared up and disrupted daily life. A similar finding was reported in a qualitative study by Wood et al. (2017) who conducted narrative analysis (NA) across 12 accounts of men with CP/CPPS in the UK. One of the three themes described by Wood et al. (2017) related to the erratic nature of the illness, which they described as undermining men’s sense of inner control and leaving men fearful about when it will worsen.

The idea of control has also been explored in two quantitative studies using the Survey of Pain Attitudes (Aubin, Berger, Heiman, & Ciol, 2008; Tripp et al., 2006). In a study by Aubin et al. (2008), when compared to a control group, men with CP/CPPS had lower beliefs of control over pain. And in a study by Tripp et al. (2006) it was found that higher levels of perceived control (as well as social support) were associated with reduced levels of pain and disability. Overall this suggests that the perception of control over bodily functioning may be challenged for men with CP/CPPS, and potentially may be linked to feelings of anxiety. However, further research would need be helpful to extend and explore the nature of this.

1.4.3. Catastrophising

Catastrophising refers to exaggerated negative thoughts that are often future oriented and associated with feelings of anxiety. A number of quantitative studies have used a standardised measure to assess this cognitive style, and found that it is heightened in men with CP/CPPS (Piontek et al., 2019; Riegel et al., 2014; Tripp et al., 2009, 2006). Catastrophising has also been found to have a close relationship with affective pain, overall pain, symptom severity, and diminished QoL (Piontek et al., 2019; Tripp et al., 2009, 2006). In particular it has been found that men reporting higher levels of catastrophising thoughts *as well as* pain-contingent rest (i.e. avoiding movement or activity due to pain) are more likely to report greater pain, disability, and depression as well as less perceived control over pain, and less social support (Tripp et al., 2006). Furthermore, ‘helplessness catastrophising’, which includes thoughts such as “I feel like I can’t go on”, was the largest predictor of affective and overall pain. Given the cross-sectional nature of this study it is not possible to draw conclusions in terms of cause, however Tripp et al. (2006) hypothese that a context of ineffectual medical therapies may be a factor in the strong presence of helplessness catastrophising, or alternatively suggest it may be that helplessness cognitions may influence a more passive/avoidant approach to pain management resulting in higher levels of pain.

1.4.4. Depression

Depression has been associated with CP/CPPS in a number of studies although there is variation in prevalence (Chung, Huang, & Lin, 2011; Hatchett et al., 2009; Lien, Chung, Lin, & Chang, 2019; Piontek et al., 2019; Wang et al., 2016; G. Zhang et al., 2011). Brünahl et al. (2017) found that 50.7% of 71 men with CP/CPPS met the clinical cut-off for depression using the Patient Health Questionnaire (PHQ-9), whilst another study also using the PHQ-9, found that 12% of 174 men met the clinical cut-off (Clemens, Brown, & Calhoun, 2008). Zhang et al. (2011) used the Hospital and Anxiety Depression Scale and found that 6.5% of 80 men met the clinical cut-off for depression. Suicidal tendencies were also reported as significantly elevated in a study that gathered data using a self-developed questionnaire from 1832 men (Mehik, Hellström, Sarpola, Lukkarinen, & Järvelin, 2001).

Depressive symptoms have been associated with higher levels of pain, and decreased physical and mental QoL (Piontek et al., 2019; Tripp et al., 2006). It has also been found to be sustained over a 2 year period, and experienced by men, and their partners (Tripp et al., 2013). Depression has also been found to be associated with sexual function, in particular orgasm function, decreased intercourse satisfaction and increased reports of non-sensuality, and similar to Tripp et al. (2013) was found to be present in men's partners (K. Smith, Pukall, Tripp, & Nickel, 2007). This suggests that the interpersonal context may be important.

Looking across a 3 year period, Chung et al. (2011) found that men were more likely to develop depressive symptoms following a diagnosis of CP/CPPS. In this study they tracked healthcare encounters of 3051 men with a recent diagnosis, whilst comparing to a control group. 5.34% of the men with CP/CPPS were confirmed to have a subsequent diagnosis of depression, whilst only 3.24% of the control group were found to have this diagnosis. After adjusting for other variables, CP/CPPS remained a significant predictor of depression. In addition to this it was also reported that there was an increased incidence of depression in men under the age of 30 (Chung et al., 2011).

This suggests that CP/CPPS may indicate a higher risk for low mood, however this relationship is likely to be bidirectional, as another study which used historical data with a sample of 13,019, found that men with a prior diagnosis of depression were at a 1.83-fold risk of having a later incidence of prostatitis (including non-chronic) (Lien et al., 2019). This was compared to a control group, and accounted for other variables (age, occupation, urbanisation, medical comorbidities, and use of anti-psychotic medications) (Lien et al., 2019). Despite this research having strength in terms of the sample size and longitudinal nature, specific information about mechanisms that may link and influence the relationship between low mood and CP/CPPS remain unclear.

In qualitative literature sudden mood changes, including low mood, irritability, frustration and anger, are found to have an association with social activity and interpersonal interactions (Hatchett et al., 2009; Jonsson & Hedelin, 2008). Jonsson and Hedelin (2008) reported a theme entitled ‘abrupt mood swings and restricted social life due to chronic pain’, which described how men coped with sudden mood changes by avoiding social contexts, the authors noticed that this resulted in a loss of self-confidence over time. However, they also reported disparity across participants, as others reported coping with mood change by continuing to function, linking this to perceived social pressures of not wanting to be seen as someone who has ‘a problem.’ Hatchett et al. (2009), analysed interviews from a mixed sample (of men and women in the US) using grounded theory, and found that half of the participants discussed negative mood changes which they said affected their overall outlook, limited their desire to be with others, and decreased enjoyment in activities. Hatchett et al. (2009) also reported that participants experienced feelings of loss for their ‘old self’ whom they perceived to be ‘happy’ and ‘normal.’

1.4.5. Disability

Disability is a concept that is not easy to define, but put simply, can be understood as the lack of societal accommodation for a person's needs (Charmaz & Belgrave, 2015). It is also therefore a construct that is relative to an individual's context, and appraisals of need in relation to this.

Quantitative literature has explored pain-related disability using the Pain Disability Index, and has been found to be associated with increased urinary difficulties, greater pain and greater pain-contingent rest (Tripp et al., 2006). Whereas perceived control over pain and social support was found to be negatively associated with disability (and pain). This highlights that experiences of disability can potentially be modified by others and by perceiving that symptoms can be controlled. Furthermore, a study by Ginting et al. (2011) found that 'types' of spousal responses to pain influenced the impact of pain on disability, with solicitous responses (e.g. "does some of my chores") increasing the negative impact of pain on disability and distracting response (e.g. "tries to get me involved in some activity") decreasing the negative impact of pain on disability although this was not significant.

Qualitative research provides a more nuanced insight into the multifaceted way in which disability can be experienced as part of CP/CPPS. In particular, limitations to activity were experienced across work, social and more intimate contexts, and were linked to physical and emotional symptoms (Hatchett et al., 2009). Hatchett et al. (2009) reported 49% of their sample felt unable to work effectively, and that disrupted work had resulted in long-term loss of career opportunities (Hatchett et al., 2009). Across two other qualitative studies, difficulties sitting were in particular highlighted as an aspect of living with CP/CPPS that was perceived to particularly interfere with and limit daily life (Jonsson & Hedelin, 2008; Wood et al., 2017). The study by Wood et al. (2017) reported that men coped with difficulties sitting by taking into account sitting arrangements, making adaptations to seating, or by ensuring breaks. This was similar to a finding by Jonsson and Hedelin (2008) whose theme 'enduring pain by performing activities and changing body positions' explained that men varied tasks as a way of ensuring they could change positions to avoid worsening pain and manage tasks. Coping strategies were also motivated by the desire to conceal illness and disability from others (Hatchett et al., 2009; Jonsson & Hedelin, 2008; Wood et al., 2017). In a study by Jonsson and Hedelin (2008), the authors wrote that the most common way of coping with limitations at work was to “avoid mentioning problems and go on performing as well as possible” (p. 548). This also draws attention to the invisible nature of CP/CPPS, and how CP/CPPS could be considered an invisible disability (A. Davis, 2005). It has been argued that invisible disabilities place a particular kind of burden on sufferers, in that they bear the responsibility for securing necessary assistance, and convincing others of the serious nature of their illness (A. Davis, 2005; Lampard & Bunsell, 2019).

Qualitative studies have also highlighted how men can experience CP/CPPS as unpredictable and erratic, and that this can also hamper men’s ability to function (Hatchett et al., 2009; Wood et al., 2017). This has been found to have a negative impact in terms of planning and engaging in daily activities. For example, Hatchett et al. (2009) found that 21% of their sample described ‘urge to urinate’ as variable, and when it increases, it is disruptive and bothersome, interrupting work and home life. Over time this is reported to limit both work and social mobility, with men for example, avoiding work opportunities due to fears that they will not be able to complete tasks.

1.4.6. Fatigue

In qualitative studies fatigue is reported as a significant part of men’s experiences of CP/CPPS (Hatchett et al., 2009; Jonsson & Hedelin, 2008). In one study, the theme of ‘disturbed sleep and disabling fatigue’ described fatigue as the most commonly cited difficulty of living with CP/CPPS (Jonsson & Hedelin, 2008). This was linked to persistent pain, and a frequent urge to urinate, which resulted in fatigue that impacted behaviour during the day. Both studies had similarities in reporting that men felt fatigue negatively affected their ability to work, and engage with social activities (Hatchett et al., 2009; Jonsson & Hedelin, 2008).

1.4.7. Coping Strategies

Two studies focused on coping strategies in particular. In a quantitative study with a sample of 222 men, nonmedical coping strategies were collected using a self-developed questionnaire, and rated in terms of their helpfulness (Turner et al., 2006). They found that the most helpful coping strategies were urinating (25.5%), warm baths (23.4%), drinking water (23.1%), walking/jogging (12.9%), and drinking cranberry juice (9.4%). The strategies perceived to aggravate were sitting (41.6%), walking/jogging (26.6%), sexual activity (24.5%), drinking coffee (16.18%) and cycling (14.3%). These findings highlight the wide variety of nonmedical strategies that were used, and also showed how some of strategies (e.g. walking/jogging) can be experienced by some men as helpful whilst for others it was unhelpful.

Wood et al. (2017), whose qualitative study aimed to explore ‘coping stories,’ also found a wide variety of strategies, including being active, utilising support, and retaining positive thinking about the future. In particular the authors described how searching for meaning was central to men coping, and that this was undermined by a lack of understanding and information about CP/CPPS. The authors also reported that men used strategies alongside a continual search for a cure.

1.4.8. Interpersonal and Social Contexts

Research suggests that interpersonal and social contexts are often implicated in men’s experiences and can play an important role in shaping this.

1.4.8.1. Social support

Some studies have explored the concept of ‘social support’ using questionnaires such as the Multidimensional Scale of Perceived Social Support, which assesses perceived support from family, friends and a significant other, as well as producing an overall rating of perceived support (Nickel, Tripp, et al., 2007; Tripp et al., 2006). Results indicate that social support (and in particular the subscale of family and friends social support) is positively associated with improved mental QoL. Social support also has stronger associations with QoL than pain severity (Nickel, Tripp, et al., 2007). Another study found increased social support had positive associations with less pain, disability, depression and catastrophising (Tripp et al., 2006).

Some quantitative research has also specifically considered how different types of responses can impact men's experiences. For example, solicitous responses (i.e. encouraging men to rest, partners completing additional chores) have been found to be associated with an increased level of disability and pain, whereas distracting responses (i.e. encouraging trying to get men involved in activities) decreased impact of pain on disability (Ginting, Tripp, & Nickel, 2011; Tripp et al., 2006). This suggests that the quality of responses from others can influence men's experiences of CP/CPPS.

Qualitative research has described that men can find it beneficial to share personal stories of illness with "someone who cares" (Wood et al., 2017, p. 911) However, Hatchett et al. (2009) reported that men (and women) with CPP often feel misunderstood by others, which they connected to negative emotions and feelings of frustration. This suggests that there is something in particular about feeling 'understood' that may be important in interactions with others.

There is also evidence that men take measures to conceal difficulties from others, particularly in social and work contexts, making it difficult for them to receive social support. For example, Jonsson and Hedelin (2008) reported that men felt driven to maintain behaviour at work and in other social contexts as if living without illness or disability. This has been linked to a perception of others being uncomfortable hearing their experiences, as well as internalised feelings of shame, and the perception of themselves to be of less value because of their illness (Jonsson & Hedelin, 2008; Wood et al., 2017). Wood et al. (2017) have suggested that this is influenced by ideas of masculinity (which is discussed further in section 1.6.4).

1.4.8.2. Intimate and sexual relationships

Quantitative research suggests that CP/CPPS influences intimate and sexual relationships, which is arguably unsurprising given that symptoms include pain in the pelvic area, and sexual dysfunction such as erectile dysfunction, pain upon ejaculation, and premature ejaculation (Bartoletti et al., 2007; Chen, Zhou, Qiu, Wang, & Dai, 2015; S. Davis et al., 2009; Mehik et al., 2001).

A study by K. Smith et al (2007) considered 38 men (and their partners) with CP/CPPS alongside a matched control group, and found that men with CP/CPPS reported significantly less desire, more erectile problems, impaired orgasm, and decreased sexual satisfaction compared to the control group, as measured by the International Index of Erectile Function. Another study, by Aubin et al. (2008), also using a control group, which adjusted for age and marital status, found that men with CP/CPPS had significantly less frequent sexual desire or thoughts, less frequent sexual activities, and less arousal/erectile function. There was not however found to be a statistical difference between orgasm function, and pleasure/satisfaction. These findings were based on a sample of 72 men who completed the NIH-CPSI, an extended version of the Brief Sexual Functioning Questionnaire, the Centre for Epidemiologic Studies Depression Scale, the Survey of Pain Attitudes, the Childhood Trauma Questionnaire, the Short Form-36, and the PSS.

It is important to note that findings indicate that sexual dysfunction does not necessarily equate to a decrease in sexual satisfaction or relationship functioning. One study reported that in a sample of 1832 men with CP/CPPS, 17.1% reported marital difficulties and 4% said that symptoms had led to relationship breakdown (Mehik et al., 2001). However in other studies, relationship functioning has not been found to differ from men without CP/CPPS (K. Smith et al., 2007). K. Smith et al. (2007) also found that there was no significant decrease in sexual satisfaction in couples when compared to controls suggesting that sexual dysfunction can provide opportunity for enhancing emotional and sexual intimacy. A similar finding was reported in a study by Aubin et al. (2008).

Sexual dysfunction has however been linked with low mood (Aubin et al., 2008; K. Smith et al., 2007). K. Smith et al. (2007) for example, found that depressive symptoms mediated orgasm function, decreased intercourse function, and increased reports of non-sexuality, suggesting a relationship between sexual function and low mood. Whilst Aubin et al. (2008) found that higher perceived stress was related to lower sexual pleasure/satisfaction, lower levels of arousal, poor erectile functioning, and worsening pain. Using linear regression models, Aubin et al. (2008) also found that depression (assessed using the Centre for Epidemiological Studies Depression Scale) was statistically significant regarding frequency of sexual activity.

It has also been suggested that some men have experiences of symptoms worsening following sexual activity, which may lead men to withdraw from sexual activity (Turner et al., 2006). It has also been linked to cognitions using the Sexual Modes Questionnaire, which found that negative thoughts towards sexual activity (such as anticipating failure, erection concerns, body-related thoughts, and negative thoughts about sex) partially mediated a relationship between pain intensity, and sexual functioning (Pereira, Oliveira, & Nobre, 2018).

Turning to qualitative studies; Jonsson and Hedelin (2008) described negative mood as impacting relationships with partners, and that erectile dysfunction made men avoid sexual activities. Together these issues were described as having negative consequences for new and established relationships, but no further details were provided. In the mixed sample study by Hatchett et al. (2009), 40% of participants described an effect on sex life, reporting that this gave rise to feelings guilt, and ‘letting others down.’

1.4.8.3. Relationships with healthcare professionals

Men with CP/CPPS are reported to be in frequent contact with a diverse range of healthcare professionals including general practitioners (GPs), urologists, psychologists, and physiotherapists, particularly around the onset of symptoms, during the diagnostic process, and relating to concerns that symptoms may indicate something life-threatening (Jonsson & Hedelin, 2008; Wood et al., 2017). Despite this, very little research has explored men's relationships with healthcare professionals, and it has been completely overlooked by quantitative studies.

Qualitative studies provide some insight, suggesting that men can feel symptoms are not taken seriously by medical professionals, which may have a negative impact, invalidating their experiences, and increasing feelings of shame (Jonsson & Hedelin, 2008; Wood et al., 2017). This formed one of three themes in the study by Wood et al. (2017), 'medical stories: blame and shame,' which describes finding diagnostic and treatment processes perplexing and unsatisfying. A personal account by Wood (2015) of seeking support from healthcare professionals suggests that this can be critical in terms of helping the sufferer feel that they are not alone. It therefore appears that these interactions may be influential in men's experiences of CP/CPPS, however further research is needed.

1.4.8.4. Connecting to other sufferers

Wood et al. (2017) found that some men connected with other sufferers via internet forums which provided opportunity for peer support but could also be experienced as overwhelming. Internet forums provide men with an opportunity to share experiences whilst maintaining anonymity. In this study it was noticed that it enabled men to appear vulnerable or powerless, producing a counternarrative to dominant concepts of masculinity. No other studies were found to report on how men may or may not utilise peer support, and if this was found to be helpful or not.

1.5. Relevant Theories, Models, and Frameworks

Given the complexity of experiences relating to CP/CPPS, its reported impairment to a sufferer's life, and the relative lack of understanding; models and theories relating to chronic illness, can provide useful frameworks for understanding (Charmaz & Belgrave, 2015).

1.5.1. The Biopsychosocial Model

The biopsychosocial model developed by Engel (1977) is frequently used in the field of chronic pain in terms of understanding and informing interventions. It is also recognised to be useful for understanding and supporting men with CP/CPPS (Adamian et al., 2020; Engeler et al., 2020).

The biopsychosocial model foregrounds a multifactorial, and integrated approach to understanding illness. It argues illness is best understood by considering biological, psychological, and social factors and was developed in response to observations that a biomedical model aligns itself with a dualistic perspective of the mind and body, which does not adequately account for the role of psychological and social processes in experiences of illness. The biopsychosocial model takes a more inclusive approach that also considers how illness interacts with a person's social contexts, and psychological world. This includes the personal meaning of illness to each individual within their unique context, and considers how this may influence, and be influenced by biological and social factors (Engel, 1977).

Grace (2000), who reviewed literature on CPP in women, found that the psychosocial element of the biopsychosocial model was often conceptualised as something to be 'included' in assessment, but argued that the current literature on CPP remains committed to Western empiricism promoting the idea that a causal explanation can be identified within a scientific model. She argues that this has resulted in a failure to consider the subjective meaning that individuals give to their experiences, and advocates for more understanding of this (Grace, 2000). Other research also indicates that healthcare professionals working with chronic pain can struggle to integrate the psychosocial aspects of the model, turning to this only after the biomedical has been exhausted (Toye, Seers, & Barker, 2017). Overall, this suggests that whilst the biopsychosocial model is advocated in current practice, there are likely still barriers associated with its application, and that further research that takes an integrated approach may be helpful in promoting this.

1.5.2. Chronic Illness as a Sociocultural Narrative

It has been argued by Bury (1982), who carried out qualitative research into the experience of people with rheumatoid arthritis, that chronic illness can be conceptualised as a ‘biographical disruption’ which he divides into three stages:

1. The disruption of assumptions and behaviours which involves attention towards bodily states that are not usually in consciousness.
2. The disruption of explanatory systems which involves a fundamental rethinking of biography and self-concept.
3. Response to the disruption involving the mobilisation of resources.

With this concept he puts forward the argument that chronic illness challenges knowledge and structures that underpin everyday life, forcing the recognition of pain, suffering, and death which may have otherwise only been considered a distant possibility or something that other people experience. Bury (1982) also argues that chronic illness does not impact the individual alone, but affects families, and wider social networks by disrupting the “normal rules of reciprocity and mutual support” (p. 169).

Bury’s model (1982) assumes that the process of adjusting to illness is closely tied to socio-cultural contexts, for example in his second stage he argues medical knowledge, as a dominant cultural framework is often drawn on. He argues that when medical knowledge is considered insufficient as is often the case in chronic illness, people draw on other social and cultural influences as a way of rethinking the self-concept. An example of this is the work of Arthur Frank, author of 'The Wounded Storyteller', who describes moving beyond ‘medical stories’ as a way of recognising and accounting for the complexity of illness experiences (Frank, 1995). In Bury’s model, in the final stage (mobilising resources), again context is important, for example how much flexibility there may be at workplaces or within friendships to accommodate change. Bury (1982) highlights that it is also in this stage that socio-economic power takes particular prominence, as the variable distribution of economic resources can compensate and offset some of the effects of disability.

1.5.3. The Self in Pain

Charmaz (1995) describes chronic illness as an *assault* to the body, and a *threat* to the self. She argued that it is a time when taken-for-granted assumptions about the unity between body and self are disrupted, and a person is forced to confront values, practices, and preferences that they held about the body in relation to their self (Charmaz, 1995, 2002).

Charmaz (1995) suggests that individuals go through a process of adaptation to chronic illness which she outlined in three stages, noting that this process is likely to occur repeatedly. The three stages are outlined as:

1. Experiencing and defining impairment or loss.
2. Making bodily assessment and identifying trade-offs.
3. Surrendering to the new self by relinquishing control over illness, giving up notions of victory over illness, and affirming one's self as tied to the ill body.

Charmaz (1995) highlights that living with an impairment is embedded in social context, where society defines 'appropriate' attitudes, actions, and activity levels, influencing how a person makes sense of self and identity, and their perception of impairment or loss. This draws on symbolic interactions, in which personal identity means the way an individual defines, locates, and differentiates self from others, and therefore indicating it is important to understand the meaning that people assign to their bodily experiences and the social contexts in which they occur.

In her study, Charmaz (1995) also noticed a difference between genders, with men more likely to place a higher stake on recapturing their past identity, and that not achieving this being tantamount to failure. This suggests that for men this process may more emotionally demanding than for women. Similarly, in a later study, she noticed that men were more likely to hold habitual views about the body that assumed invincibility, agelessness, increasing functioning and strong personal control which subsequently often led to a struggle against illness and depression when this was not possible (Charmaz, 2002)

1.5.4. Theories of Masculinity

Masculinity refers to the social processes that construct what it means to be a man. It is closely related to the idea of gender, which Connell (2009) defined as “the structure of social relations that centres on the reproductive arena, and the set of practices that bring reproductive distinctions between bodies into social process” (p. 11). Health issues have been found to be an important arena in which men navigate ideas of masculinity, as well as being active in their production (Charmaz, 1994; Connell, 2000; Courtenay, 2000b, 2000a; De Visser & Mcdonnell, 2013; O’Brien, Hunt, & Hart, 2005). Given the invisible nature of CP/CPPS, it can be argued that social processes are even more crucial to a sufferer’s experience, as it is reliant on the sufferer to enter (or not enter) into an explicit social process if they want to share experiences of CP/CPPS with another person (Connell, 2000; A. Davis, 2005).

Masculinity has been identified as implicated in men’s experiences of CP/CPPS in a qualitative study by Wood et al. (2017), in which the authors reported that masculinity appeared to restrict men’s accounts of living with CP/CPPS, particularly when it might portray vulnerability or powerlessness, “as if men were both afraid to tell these stories of broken masculinity – and were not used to being ‘heard’ or fully understood” (p. 913). Furthermore, Toye et al. (2014) conducted a meta-ethnographic study of 32 qualitative papers on the experiential aspects of CPP (including two papers with samples including men) and reported that there were differences between sex. They tentatively suggested that gender may be implicated and reported that men were more focused than women on receiving validation that their pain was not life threatening. They also reported that, when compared with women, men did not report the social construction of pathology, the elevation of experiential knowledge, and the embodiment of knowledge through community, suggesting that men may not be engaging with peers in the same way that women do. It is however hard to draw conclusions from this due to the lack of research into men's experiences.

It is important to note that as a social construct, masculinity is culturally specific. In western society, it has been argued that hegemonic masculinity, representing traditional roles of power and authority, is a dominant construct of maleness. Aspects of this include the denial of weakness or vulnerability, emotional and physical control, the appearance of being strong and robust, the dismissal of any need for help, a ceaseless interest in sex, the display of aggressive behaviour and physical dominance (Courtenay, 2000a). Hegemonic masculinity has however received some criticism for projecting ideas that it is unitary and static when evidence has shown that even within the same societies and communities there are multiple notions of masculinity, and influenced by a number of factors such as age, ethnicity, social class and sexuality (Connell, 2000, 2009). Therefore, the concept of masculinity should be considered as a process which is multidimensional, in order to avoid reinforcing binary distinctions which obscure difference among men (Courtenay, 2000b).

1.6. Rationale for the Study, and Relevance to Clinical Psychology

Current research indicates that CP/CPPS is a prevalent and debilitating condition which pervades almost all aspects of sufferer's lives. As a chronic illness with unclear aetiology, and no curative treatment, it is also clouded by a lack of understanding, which arguably exacerbates suffering (Jonsson & Hedelin, 2008; Showghi & Williams, 2012; Wood, 2015; Wood et al., 2017). As highlighted in this introduction, research into men's experiences of CP/CPPS is lacking, and has largely utilised quantitative methods which have been criticised for underestimating and underrepresenting men's experiences (Riegel et al., 2014). In particular, the current research base gives limited insight into how men's experiences of CP/CPPS may connect with relationships, and wider social contexts. This is an important consideration not only because studies have highlighted that social (e.g. spousal responses, work environments), and cultural factors (e.g. masculinity) are implicated, but also because it can draw attention to new avenues for support and intervention (Hatchett et al., 2009; Morison, Lyons, & Chamberlain, 2017; Tripp et al., 2013; Wood et al., 2017).

Research which takes an in-depth approach to understanding men's experiences of CP/CPPS, is therefore an important contribution to the evidence base, which can inform future research, policy, guidelines, and service provision, all of which may be of benefit to sufferers. Furthermore, a methodology which foregrounds men's subjective accounts of their lives can be of particular value as it supports the integration of experiential accounts with medical understanding, which has been argued to improve adherence and outcomes (Carroll, 2017; Charon, 2006). This is in line with current health policies that emphasise patient experiences as being central to successful clinical interventions (Morison et al., 2017). It can also support an understanding of illness as multifaceted and complex, involving biological, social, and psychological factors, which is promoted in current guidance for CP/CPPS (Engel, 1977; Engeler et al., 2020; Rees et al., 2014).

This is of relevance to the field of clinical psychology as current guidance on the management of CP/CPPS recommends support from a multidisciplinary team, which includes the input of clinical psychologists (Engeler et al., 2020; National Insitute for Clinical Excellence, 2019; Rees et al., 2014). In the UK this is often within the context of chronic pain management services (Faculty of Pain Medicine, 2015). Although it can also be of relevance to primary care settings, where clinical psychologists are increasingly involved in supporting people with long-term conditions (NHS England and NHS Improvement, 2018). Therefore, clinical psychologists can play a fundamental role not only in developing and delivering psychologically informed interventions for men with CP/CPPS, but also in consulting with other professionals, and shaping service design and provisions. This is however reliant on the current evidence base, and so increasing research which provides nuanced insight into the experiences of men with CP/CPPS, is likely to be of benefit.

1.7. Research Aims

Given the rationale outlined, the overall aim of this research study is to increase understanding of men's experiences of living with CP/CPPS. In particular, it aims to explore how men describe and make sense of their experiences, and to consider how this may influence and be influenced by interpersonal and social contexts.

1.8. Research Questions

1. How do men experience living with CP/CPPS?
2. How have their experiences of CP/CPPS influenced and been influenced by social contexts and relationships?

2. METHODS

This chapter describes the ontological and epistemological position of the researcher, before going on to outline methodology and method. It aims to be transparent about the position of the researcher, and how this may influence the research process (Levitt et al., 2018; Nowell, Norris, White, & Moules, 2017).

2.1. Ontological and Epistemological Position

Ontology concerns ideas we hold about the nature of the world, whilst epistemology focuses on the theory of knowledge which concerns *how* we might come to know about the nature of the world (Willig, 2013). Assumptions made in relation to ontology and epistemology are therefore fundamental for defining and guiding the research process and outcomes (Braun & Clarke, 2013; Chamberlain, 2015).

A critical realist position was adopted for this research. Taking this position was considered appropriate in terms of aiming to produce knowledge that can have ‘real-world’ implications in terms of furthering research and advocating for change in structures that support men with CP/CPPS.

Critical realism is an ontological position that sits between two dominant and opposing ontological positions: realist and relativism. A realist position assumes that there are social and psychological processes that exist, and that it is possible for these to be identified and described by the researcher, whereas relativism assumes that there is no absolute truth, instead that there are multiple constructed realities (Willig, 2013). A critical realist position sits between these in that it acknowledges a reality to events (observable and experiential phenomena) but ascertains that this “sits behind the subjective and socially-located knowledge that a researcher can access” (Braun & Clarke, 2013, p. 27). Critical realism is therefore akin to a contextual constructionist position in that it acknowledges that subjectivity is inherent in all knowledge production, and that knowledge is temporally and socially dependent (Madill, Jordan, & Shirley, 2000).

In relation to this project, it is therefore assumed that there is a reality to men’s experiences of living with CP/CPPS, but accounts of this will only ever be partial and influenced by the social, cultural and historical structures that constrain and shape meaning and understanding of both participants and researcher. As a result, it is accepted that knowledge generated from this study can never be objective, but that it can still provide important insight towards an understanding of some ‘truth’ about men’s experiences of living with CP/CPPS.

2.2. Methodology

2.2.1. Rationale for Taking a Qualitative Approach

The aim of this study is to increase understanding of men’s experiences of living with CP/CPPS; in particular to explore how men describe and make sense of their experiences, and to consider how this may influence and be influenced by interpersonal and social contexts.

In the field of health research, it is increasingly recognised that a qualitative approach is well suited to examining closely the experience, perspective, and meaning of illness and wellbeing from the viewpoint of the patient (Rohleder & Lyons, 2015). Furthermore, qualitative research is considered an exploratory approach that is well suited to developing new understandings or producing original insight (Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017). As outlined in the introduction, the majority of research into men’s experiences of CP/CPPS has utilised quantitative methods, and therefore conducting qualitative approach can be considered complementary in providing more nuanced understanding personal experiences, and also being sensitive to relational and contextual issues (Morison et al., 2017).

This also fits with the theoretical perspective underpinning this study, namely narrative illness theory, which argues that personal experiences and interpretation of illness are important to better understand ill health and to foster more effective interventions and self-management (Kleinman, 1988).

2.2.2. Rationale for Using Thematic Analysis

Thematic analysis (TA) is defined as a *method* (rather than a methodology) “for identifying, analysing and interpreting patterned meanings or themes” (Braun, Clarke, & Terry, 2015, p. 95). It is unlike other qualitative approaches in that it is not tied to a theoretical framework and can be used within different ontological, theoretical and epistemological positions.

TA was selected for this project for various reasons. Firstly, it’s theoretical flexibility facilitates a rich and detailed account of the data that is well suited for exploring personal experience and meaning (Braun et al., 2015; Nowell et al., 2017). Secondly, it is well suited for identifying and interpreting patterns across heterogeneous data, which was anticipated might be the case for this research study (Braun & Clarke, 2006). Thirdly, no other study exploring men’s experiences of living with CP/CPPS has adopted TA. And finally, TA is considered well suited to researchers in the early stages of their research career, which is applicable in this case (Nowell et al., 2017).

IPA and NA were also considered, and both may have suited this project. They were however decided against, for several reasons. The first was that both IPA and NA have already been utilised in previous research on men’s experiences of CP/CPPS (Jonsson & Hedelin, 2008; Wood et al., 2017). NA focuses more on *how* the story is told, which was not within the realm of this study’s aims. Regarding IPA, whilst well suited to the research aims and questions, it did not offer the same theoretical flexibility that TA could. Additionally IPA is better suited to a homogenous sample, which was not anticipated with this study (Braun et al., 2015; J. Smith & Osborn, 2008).

TA has received some criticism for being ‘unsophisticated’ in comparison to other qualitative approaches, however this is less to do with the method and more about a researcher’s application, transparency around epistemological position, and reflexivity in the process of analysis (Braun & Clarke, 2006; Braun et al., 2015). Steps have therefore been taken to ensure that these issues are addressed.

2.2.3. Involvement of Men Living With CP/CPPS

Men living with CP/CPPS have been involved in the development of the research aims and questions, design, ethical considerations, and analysis. Working with experts by experience in the research process is reported to have a number of benefits such as improved quality, relevance, recruitment, credibility, and translation into clinical practice (Domecq et al., 2014; Gooberman-Hill et al., 2013; INVOLVE, 2012; Mjøsund et al., 2017). It is also an issue of ethics as it addresses power imbalances in the arena of publicly funded research, and is recommended as good practice by the National Institute for Health Research (Brinkmann & Kvale, 2017; Gradinger et al., 2015; UK Public Involvement Standards Development Partnership, 2019).

Involvement has included consultation at every stage of the process with the principal supervisor, who has over 15 years experience living with CP/CPPS. In addition to this, the following steps were also taken (in chronological order):

1. During development of the research proposal, consultation was sought from a group on social media and from discussion with an expert by experience. Feedback was supportive of conducting research into men’s experiences of CP/CPPS and feedback was used to inform direction of the research and approach to interviews (see Appendix A for overview of responses and reflections from online consultation).
2. Consultation on research aim and questions, design, and interview schedule was sought from a support group for men with CP/CPPS. Participants expressed support for the research aims and questions, and gave the following feedback:
    a. All members expressed strong motivation for the research to be conducted and disseminated to raise awareness, reporting that they felt that experiences of the illness were under-recognised,

    particularly within the medical profession, and that this exacerbated distress.
    b. A diversity within the group was expressed in terms of how often men had spoken to other people about their experiences, with some men reporting that this is limited to the support group and medical professionals. They predicted that some participants may not have had many opportunities to speak openly about their experiences. Based on this they advised arranging the interview schedule to help guide and support men through this process (i.e. using introductory questions before moving on to talk about relationships or more intimate subjects).
    c. They shared previous experiences of feeling ignored by professionals and reported that it is important that the interviews offer a space for men's stories to be heard.
    d. Members suggested adding a question around how CP/CPPS influences beliefs about the future.
3. As much as possible, at the end of interviews, participants were asked for feedback on how they had found the interview process and if they had any suggestions for future interviews. This informed, for example, asking men at the beginning of the interview what language they prefer to use when I refer to CP/CPPS.
4. One transcript was shared with a participant to provide opportunity for feedback and improve validity.
5. It is also planned for results of analysis to be shared with participants and the support group to gain their feedback on the 'fit' of findings.

2.3. Research Procedure

2.3.1. Participants and Recruitment

2.3.1.1. Inclusion criteria

The inclusion criteria for the project stipulated that participants must be aged 18 years or older, based in the UK, have a good level of spoken English, and have a diagnosis of CP/CPPS for a minimum of 1 year. The latter criterion was agreed based on feedback from the principal supervisor that the initial months of CP/CPPS can be a time of acute distress and therefore it was considered to be ethically responsible to exclude men who had the diagnosis for less than a year.

2.3.1.2. Recruitment procedure

Participants were recruited from a support group, three online forums and contacts of the principal supervisor. Using a variety of different forums was considered helpful in gaining access to a diverse group of men. Members of the support group and online forums were provided with a brief overview of the project, the inclusion criteria, information regarding what participation would involve, and the researcher’s contact details inviting them to get in contact if they were interested to participate (see Appendix B for recruitment post on online forums). Consent from administrators of the support group and online forums was sought ahead of introducing the project.

21 men made contact to express an interest within the first 24 hours. All men were thanked for showing an interest, inclusion criteria were checked, and an information sheet with more detailed information was shared to support a process of informed consent (see Appendix C for the information sheet).

2.3.2. Data Collection

2.3.2.1. Semi-structured interviews

Data was collected using semi-structured interviews, as they are well suited to exploring lived experiences from the participant’s point of view (Kvale, 1996; Madill & Gough, 2008).

It had been estimated that between 8–12 interviews would allow meaningful analysis of the entire data set (Guest, Bunce, & Johnson, 2006). In discussion with the principal supervisor, the decision was taken that eight interviews would provide adequate data to meet the study aims. This was decided after five interviews were completed, noticing that they were rich in the information shared (Kvale, 1996; Levitt et al., 2017). In total nine interviews were conducted however one participant was excluded from analysis after failing to return a signed consent form.

2.3.2.2. Interview schedule

An interview schedule was developed to explore participants' experiences of living with CP/CPPS (see Appendix D for the interview schedule). Questions were intended to gather information in line with the research questions and therefore focused around two aspects: firstly, their experiences of living with CP/CPPS, and secondly, how their experiences of living with CP/CPPS has influenced or been influenced by social contexts and relationships.

Questions were framed openly and prompts such as "can you please tell me a bit more about that" were used to encourage rich descriptions and to gain 'closeness' to the lived world of the participants (Kvale, 1996). This included gentle probing to understand meanings associated with experiences, and allowing participants the opportunity to elaborate on their own perspectives and self-understanding (Kvale, 1996). Retaining flexibility with the schedule was also considered helpful to ensure interviews provided space for their stories to be fully heard, in line with feedback gathered during consultation with a support group.

Some specific questions relating to demographic information were also included. This related to age, ethnicity, sexuality, gender identity, relationship status, and duration of illness. These were asked at the beginning of the interview, in order to provide context, and to build rapport.

2.3.2.3. Interview procedure

Interviews were scheduled on a first-come-first-served basis after men had read the information sheet and confirmed they met inclusion criteria. Participants were invited to meet at a location and time that was mutually convenient. When meeting in person was not possible (e.g. due to geographical distance or time constraints), interviews were also offered over Skype.

Before the interview commenced, the information sheet and consent form were reviewed together, and participants were given opportunity to ask questions (see Appendix C for the information sheet, and Appendix E for the consent form). Written consent was provided before proceeding in face-to-face interviews. When interviews were conducted over Skype, verbal consent was provided before proceeding, with the agreement of sending a signed consent form immediately following the interview.

During the interview the schedule was used flexibly in terms of the ordering of questions, altering the form of the question and following up on information provided by the participant. This was done to promote an atmosphere of safety and openness, in which the participants' accounts were carefully listened and attended to. Following the interviews, participants were provided with a debriefing sheet and invited to give feedback on how they had experienced the process (see Appendix F for the debrief sheet).

2.3.3. Ethical Considerations

2.3.3.1. Ethical approval

Ethical approval for the project was sought and granted by the University of East London School of Psychology Research Ethics committee (see Appendix G for a copy of ethical approval). Three minor amendments were requested relating to study title and participant reimbursement which were approved (see Appendix H for ethical amendment approvals).

2.3.3.2. Informed consent

An information sheet was provided to participants informing them of the purpose and procedure of the study, confidentiality, and their right to withdraw up until the point of analysis (Brinkmann & Kvale, 2017). Signed consent forms were used as a way of participants formally indicating that felt informed and consented to their data being collected and analysed.

2.3.3.3. Debriefing

All participants received a debrief sheet which thanked them for their participation, reiterated their right to withdraw, and provided contact details of the researcher, principal supervisor, and chair of the school of psychology research ethics sub-committee (see Appendix F).

2.3.3.4. Confidentiality

Transcripts were anonymised by using pseudonyms, and by removing any potentially identifying information. They were stored in a secure environment which only the researcher had access to and shared with the research supervisor and examiners as required. This research report maintains anonymity by providing no identifying data. Interview recordings were stored in a separate secure environment and will be destroyed after successful examination.

2.3.3.5. Participant distress

The interview was recognised as an interpersonal situation in which discussions were not neutral and potentially including issues that were sensitive (Kvale, 1996). Risk of distress for participants was assessed and considered to be low to moderately likely. Participants were made aware that the subject matter may be emotive and at the end of interviews they were provided with information for charities that offer 24-hour support. Clinical judgement was used to respond to distress appropriately and if necessary, to pause or cease the interview process.

2.3.3.6. Adjustments

Symptoms of CP/CPPS can make it uncomfortable to sit for extended periods, which was anticipated to impact interviews. This was discussed with men ahead of the interview and reasonable adjustments, in line with the UK Equality Act (2010), were made. This included providing men with a choice of interview location and informing them that they can take breaks, or end the interview, at any time. When the interview was held in person at the University of East London, a room with cushioned seating was provided, and men were invited to sit or stand as they preferred.

2.3.3.7. Reimbursement

Participants were provided with a £10 Amazon voucher and reimbursed for travel costs incurred. This provision was an amendment to the study's original ethical approval, after the researcher became aware that it was available. It was utilised on the basis of helping to remove financial barriers to participation (UK Public Involvement Standards Development Partnership, 2019).

2.4. Analysis

The process of TA was informed by Braun and Clarke (2006). Within this an inductive approach was adopted which means themes were "data-driven" and strongly linked to the data itself (Braun & Clarke, 2006, p. 83). The analysis was conducted at a latent level which involved interpretation and consideration of underlying ideas, assumptions, conceptualisations and ideologies that may inform the content of the data (Braun & Clarke, 2006).

2.4.1. Identifying Themes

The process of identifying themes involved six phases as outlined by Braun and Clarke (2006). To address criticisms of TA as previously highlighted, some additional steps were taken to improve trustworthiness and are outlined below (Nowell et al., 2017).

2.4.1.1. Phase one: familiarisation with the data

Familiarisation with the data was achieved via repeated and active reading. Part of this included the process of manually transcribing the data set. An orthographic approach to transcription was used (see Appendix I for transcription key). This aimed to produce a thorough record of the words spoken, with less importance placed on non-semantic sounds, although efforts were taken to record pauses, laughter, and hesitations such as 'erm' or 'err' (Braun & Clarke, 2013). During this process of prolonged familiarisation, some initial reflections were noted in the researcher's reflective journal (see Appendix J for excerpt from reflective log) (Nowell et al., 2017).

2.4.1.2. Phase two: generating initial codes

The data was then reviewed again, and initial codes were systematically defined. Codes are considered “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p. 63). ‘Complete coding’ which aims to identify anything and everything that is relevant to the research questions was adopted (Braun & Clarke, 2013). Codes were recorded using Microsoft Word review tool. (see Appendix K for an excerpt from coded transcript). An excerpt of one of the coded transcripts was shared with the principal supervisor as a way of improving credibility of coding.

2.4.1.3. Phase three: identifying themes

Themes and subthemes began to be identified by analysing codes and organising them into broader themes, via such processes as coupling codes with overlapping meanings, to inform a broader theme. This was done using a table in Excel as this enabled systematic sorting of the codes whilst simultaneously drawing out a map of how the codes might group together. This process was supported by engaging in reflective discussions with a TA supervision group.

2.4.1.4. Phase four: reviewing themes

Themes were then reviewed to consider if they cohered meaningfully together, whilst also maintaining clear and identifiable distinctions (Braun et al., 2015). A intermediate thematic map of the data was created to aid this process, and themes, subthemes and coding that matched with quotes, were shared with the research supervisor, who was able to provide feedback on the themes from the perspective of an expert by experience as well as a researcher in the field (Braun & Clarke, 2006). Based on feedback and further reviewing there was one further intermediate map before the final thematic map was created (see Appendices L and M for intermediate maps, and N for final thematic map).

2.4.1.5. Phase five: naming themes

Themes (and sub-themes) were then assigned names. In order to increase accessibility and utility of findings, this study presents themes using short phrases or sentences that “summarise key ideas while preserving the complexity of the phenomena” (Sandelowski & Leeman, 2012, p. 1407).

2.4.1.6. Phase six: summary of themes

The final stage of the analysis was writing a summary of the themes and subthemes. Efforts were taken to provide thick and articulate descriptions of each theme, the assumptions that underpin it, and their implications (Braun et al., 2015). Results are presented and discussed in such a way as to enhance utilisation and permit readers to assess the transferability of findings to contexts outside of the study (Sandelowski & Leeman, 2012). This meant attending closely to the language, using it concisely, and clearly summarising.

2.5. Methodological Integrity

Methodological integrity has been described by Levitt et al. (2017) as “the methodological foundation of trustworthiness” (p. 17). In qualitative research, the methodological integrity of a study is assessed primarily in terms of its fidelity to the subject matter and utility in achieving research aims (Levitt et al., 2018, 2017). Steps taken to ensure integrity in this study were:

- Transparent and detailed reporting of process, rationale and decision-making;
- Grounding of research findings with thick descriptions, evidence, and relevant contextual information (Levitt et al., 2017; Nowell et al., 2017);
- Managing the influence of the researcher over the analytical process by cross-referencing coding with principal supervisor, using peer supervision, and the provision of excerpts within the final report (Nowell et al., 2017);
- A reflexive position and transparent reporting on researcher’s positionality and how this may have influenced data collection and analysis (Nowell et al., 2017).

2.6. Reflexivity

In line with the critical realist epistemology, researcher reflexivity was attended to throughout the project, acknowledging that the researcher's subjectivity and relationship to the subject matter is influenced by personal values, history, and social context (Levitt et al., 2018, 2017; Sandelowski & Leeman, 2012). This was recorded using a reflective diary (see Appendix O for excerpt from during interviews) (Braun & Clarke, 2013). This is considered again in the final chapter.

2.6.1. Personal Reflexivity

Initial interest in this subject came out of an experience I had in a professional setting (primary-care psychological therapies service), in which I met with a client who had CP/CPPS. It was the first time I had heard of the condition, and through listening to his story, and my subsequent attempts to find accessible information or resources, I became aware of how neglected, and hidden the illness was. This experience gave rise to feelings of empathy, which has influenced how I have approached and developed this study. It has, for example, influenced choices around prioritising men's involvement in the development of the research questions, in the selection of qualitative methodology, and in the interview process itself, by allowing adequate space for men to be fully heard.

I am aware that my background, and wider personal experiences will also influence the research process. I identify as a White British, heterosexual cis female in my mid-thirties who is currently working as a trainee clinical psychologist for the National Health Service (NHS) and studying at the University of East London. I do not experience chronic illness or disability, and my gender differs from that of the participants. My own values align closely with systemic approaches to understanding personal experiences, which is in part influenced by my professional training. Overall these have contributed to a critical and context-sensitive approach to understanding human experiences, fostering an interest in how physical health and illness interact with psychological and social factors. These experiences have influenced my approach to the subject matter and inevitably influenced the focus of the study.

I have sought to be critical of my own views and positioning, and how this may have influenced the research process, by using a reflective diary and discussing this with the principal supervisor. I have tried to attend to issues relating to difference by considering the context of research, and the assumptions (particularly gendered assumptions) that are likely to be negotiated in the interview process itself (Lefkowich, 2019; Williams & Heikes, 1993).

3. RESULTS

This chapter outlines findings from analysis of eight interviews, using the process described in the preceding chapter. In line with critical realist epistemology, findings are recognised as interpretations. Analysis resulted in the development of three themes and 12 subthemes (see Table 2). To provide context to these results, demographic information is summarised first.

3.1. Demographic Information

Participants represented a wide range of ages: the youngest participant was 28 years and the oldest participant was 68 years. The mean age was 48.9 years, and the median age was 45 years. There were seven participants (87.5%) that identified as White British, with one participant identifying as White.[2] Seven participants identified their sexuality as heterosexual (87.5%), and one participant identified as gay. All participants (100%) described their gender identity as male. All participants (100%) reported that they were in committed relationships.

Duration of illness experienced by participants was wide ranging. The shortest duration was 3 years and the longest duration was 47 years. The mean duration was 15.4 years, and the median duration was 11 years. There was high heterogeneity in reported physical symptoms, with variation in the presence, bodily location(s), and severity of pain in the pelvic region, urinary frequency, urinary urgency, and sexual dysfunction.

Please refer to Table 1 for a summary of key demographic information for each participant.

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[2] Participant did not disclose nationality

Table 1. *Demographic Information of Participants*

Participant[3]	Age	Ethnicity	Gender Identity	Sexual orientation	Duration of Illness (years)	Relationship Status
Bob	68	White British	Male	Heterosexual	10	Relationship
Callum	28	White	Male	Heterosexual	3	Relationship
Filip	43	White British	Male	Gay	10	Relationship
Harry	40	White British	Male	Heterosexual	22	Relationship
Jeremy	45	White British	Male	Heterosexual	11	Relationship
Liam	57	White British	Male	Heterosexual	3	Relationship
Matt	66	White British	Male	Heterosexual	47	Relationship
Sebastian	44	White British	Male	Heterosexual	17	Relationship

3.2. Overview of Themes and Subthemes

The three themes and 12 subthemes that were developed from analysis of the data are summarised below (Table 2), and depicted using a thematic map (Appendix N). Some of the themes connect with others via interrelated subthemes which are outlined in descriptions below, and in the thematic map.

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[3] All names are pseudonyms

Table 2. *Overview of themes and subthemes*

Theme	Subtheme
Theme 1: Trying to make sense of what is "wrong" in a "spiral of confusion"	• Why me, why *now*? • Is it cancer, am I dying? • Even the doctor doesn't know • "No escape," what does that mean for my future? • Looking for alternative explanations
Theme 2: Managing day-to-day with an illness that is debilitating and unpredictable	• Some days I can't do anything • It's hard to predict so I'm always thinking what if? • Searching for "answers" as a way of keeping hope and learning what helps
Theme 3: Sociality and isolation	• Withdrawal from social activities • Shame and stigma • Finding someone who listens • "Strain" and proximity in intimate relationships

3.3. Theme 1: Trying to Make Sense of What Is "Wrong" in a "Spiral of Confusion"

This theme represents a process of searching for information that participants thought would might help them to make sense of their experiences. Participants of this study recalled feelings of confusion and shock at the onset and subsequent persistence of symptoms, and it was assumed that there was something "wrong", which would be resolved through medical intervention. When assumptions relating to illness were not met, and a lack of satisfactory information provided, participant's distress was perpetuated in the context of uncertainty and fear that they may never "escape," and that symptoms may indicate something life-threatening.

This theme interrelates with the second theme, as making sense connects with a way of managing day-to-day when it is considered a strategy for keeping hope, and learning what can be helpful. Understandably this strategy also influenced how participants made sense of CP/CPPS, which was of crucial concern. There is thus a bidirectional and interactive relationship between these two themes.

3.3.1. Why Me, Why *Now*?

Feelings of shock and disbelief relating to the persistence of symptoms affecting the pelvic region, urinary and sexual function were recounted by participants of this study, suggesting that they were unexpected, and challenged assumptions held about their health. In particular participants questioned why *them?* And, why *now*? And for some this was qualified by referring to their age, suggesting that their assumptions about health also related to age.

> **Sebastian**: you know chronic pain, urinary dysfunction, dribbling you know it's just not what you should be experiencing as a red blooded man or woman at a young age you just feel (..) you just feel that maybe in your 70s, 80s, 90s, you know you can understand that things will start to fall apart and break down but and although it's horrid it's for later in life it's a horrid thing for later in life it's not for being a young man

> **Jeremy:** you know when you were young it's just everything works and all of a sudden you sort of (.) you know I didn't consider myself as particularly old you know (.) 35 (.) to get this … so I felt I was a bit sort of young to be having such sort of problems … maybe [it's] some sort of male thing to worry about sex like that but it does sort of just like (.) well (.) nothing's working and I'm still young so why isn't it working

3.3.2. Is It Cancer, Am I Dying?

Participants described periods when they were overwhelmed by "not knowing" why symptoms were occurring, particularly in the earlier stages of the illness when symptoms persisted, and before CP/CPPS may have been discussed.

Questions that ran through their mind were recalled, and indicated that there was an assumption that something was “wrong” whilst wondering what it meant.

> **Jeremy:** You don’t know really know what’s happened to you … you just don’t know what’s wrong with you why (.) why am I painful down here it’s hard for me it was just hard to get my head round

And catastrophic thoughts relating to serious illness (such as cancer) which propelled high levels of anxiety and fear were also recounted.

> **Liam:** I had no idea what the problem was uh (sigh) you know is it cancer what is going on here is it testicular cancer whatever it can be the worst things went through my mind

> **Matt:** It was mainly scary it was frightening what is this is it anything more serious and that was (..) for the first (..) you know I mean for a long period of time that was the main problem … the main negative impact was erm (.) was really just anxiety and what is this and is this cancer basically

Information received in the context of not knowing could provide some relief. For example, some participants described feelings of anxiety as being partially relieved when medical investigations ruled out more serious conditions. And although Filip and Jeremy described relief that CP/CPPS was identified, largely this was felt to be “vague” and not provide enough information regarding the cause. Therefore, worries and concerns about a more serious illness, yet to be identified, were sustained.

> **Filip:** I was always permanently thinking well I know I hadn’t got stones and there was no sign of cancer from the cystoscopy but in the back of my mind I always thought there was something deeply wrong downstairs erm (.) and what the future might hold for that was there something deeper inside that no-one had diagnosed?

> **Jeremy:** they call it chronic pelvic pain syndrome (.) again which is just a general (laughs) ‘we don't know what it is or what causes it’ (laughs) so that worries you a bit like well <u>what does cause it</u>?

3.3.3. <u>Even the Doctor Doesn’t Know</u>

Participants of this study sought support from medical professionals (primarily GPs, but also urologists) and recounted unsatisfying experiences. Dissatisfaction appeared to come from an initial and implicit trust that medicine would help them to make sense of their experiences, provide “answers”, and “cure” symptoms. Encounters with doctors, particularly in the initial period, were often protracted, involving a process of referrals and investigations, the exclusion other illnesses, and trials of medication. A lack of biomedical evidence, and the impression that doctors didn’t provide give clear explanation, or weren’t interested, often resulted in increased distress, with fears that if the doctor can’t help them then who can?

> **Harry**: when you are younger you expect doctors to magic up something you expect them to have the answer to everything and you know (.) largely they don’t have the answer or they think let’s try this because we don’t have the answer and they give you some tablets to take and sometimes it goes away and sometimes it doesn’t and you have no idea so it is very erm (..) in that period it is just really confusing

As Harry alludes to above, participants often described taking series of prescribed antibiotics. Some of the participants reported experiencing relief whilst taking medication, but for others they were associated with unwanted side-effects, and gave little improvement, challenging hopes that the medical profession has the “answer”, adding to negative feelings.

> **Callum:** I met this GP and he gave me these doxycycline and he said it will probably clear up in a week’s time or two weeks’ time and err nothing no change so … I was like well what do I do now so I eventually saw a

> urologist and he gave me antibiotics and still nothing erm (.) and I felt completely lost because I hoped that Western medicine would cure me

> **Jeremy:** it's a weird situation but you can see that they just they [doctors] don't know what the answer is they just have a list of things that they've tried (.) previously that may work and that's it. **Researcher:** And how do you feel about that now? **Jeremy:** Well it's one of those you know it’s (..) uh (.) I like watching Star Trek and thinking all things science fiction that it is just a case of someone waves something over you and it's fixed but actually when you have anything wrong with you do realise that a lot of the time they [doctors] don't know what causes everything so they just it's just guesswork on their part (..) and it does make you feel again it makes you because you're already feeling pretty crap with this thing is like well so no one knows there is no solution

As part of this process of trying to make sense through medicine, participants described investigations in which other illnesses were excluded, during which they mainly heard what had *not* been identified, perpetuating the state of not knowing. This was particularly frightening for some, not only because it left them wondering what was happening to them (‘is it cancer, am I dying?’), but also gave rise to situations in which participants felt it was implied that their experiences were not ‘real,’ and that they may be denied support.

> **Sebastian**: she’d [consultant] ran the tests and the culture was negative she couldn’t pick anything up she said despite the signs and the symptoms and the discharge she said it was all in my head and ‘it’s because you feel guilty for some reason’ and often men do feel guilty for things like this but she said ‘it’s all in your head and you should go away and get on with your life’ and (.) subsequent to her telling me that and me just (.) being (.) in utter disbelief that she’s denying not just the symptoms (.) the symptoms are real enough but also there were physical signs and I was saying to her ‘well this isn’t normal for me’ and she was saying ‘no no it’s all in your head’ (.) ‘off you go’

Participants often suggested consistent and clear information from doctors would be helpful, particularly around the limitations of current understanding and the rationale for tests or interventions, as well as reassurance that their experiences are worthy of help.

> **Researcher:** what do you think needs to really happen to make it easier for people in the future living with CP/CPPS? **Filip:** I think information absolutely there should be a flow chart that people know about when they are going through a route that they are going through to rule out other things and then reassurance when you get to the other end stage that you are not just a catch-all basket not none of the above it's D and therefore no help I think it needs to be much more positive … it's just the reassurance and the information really that is the key

3.3.4. "No Escape," What Does That Mean for My Future?

The chronic (albeit fluctuating) aspect of the illness was identified as particularly frightening, and one that participants struggled to make sense of, unsure of what it meant to have a future with CP/CPPS. This appeared to be linked with the initial assumption that the illness could be resolved, but also amplified by a lack of space or information to help them consider what it might mean to live well with a long-term illness. This was described as often accompanied by heightened feelings of despair, hopelessness, and for some suicidality. CP/CPPS as something chronic was difficult to accept.

> **Jeremy:** there's literally no one to talk to and there's no one to ask about it and there's no solution to it so you do feel like it is that it is that literally all I'm going to do now is have this for the rest of my life because then no one can tell you if it is going to stop so yeah it's very very daunting

> **Liam:** the first six-eight months (sigh) again you think 'my goodness what does the future hold for me' every other day I was in agony and you know is the rest of your life going to be like this

3.3.5. Looking for Alternative Explanations

Feeling unsatisfied with the explanations provided by medicine, it was reported that participants began to seek out alternatives from wider contexts. This included descriptions of searching the internet, reading books, meeting with psychologists, physiotherapists, other sufferers, and analysing their own histories and patterns of behaviour. Underpinning this search was an assumption that explanations might guide effective treatments, allowing them to “escape.” This was often done (initially) in a state of desperation.

> **Filip:** in those early days of pain you almost grasp at anything so anyone who offers you anything any potential cure or anything that might get to the bottom of it you just run with it

> **Callum:** I began to do my own research and realised that this was a bigger problem and there were so many other guys and they had gone down the antibiotic route and they saw no improvement in their symptoms so that is when I just decided to erm (.) err take my own journey

Participants reported that doing this can be both hopeful and scary, complicated by the heterogeneity of the condition, and the variety of unsubstantiated explanations for it that can be found. As Harry describes below, participants can find the opposite of the answers they are hoping for, or ones that challenge their beliefs.

> **Harry:** there is all kinds of scary stuff out there [on the internet] and because it’s erm all badged under one generic name chronic prostatitis/chronic pelvic pain whatever you want to call it (.) you don’t know if you have the same thing as those people or if you have something different … you read some stuff that has never happened to me but you think oh you know is that a natural progression of this thing can it just morph into something completely … so it is pretty scary and

> the content out there is unregulated and because there is currently no science behind it you err it's just uncertain

> **Sebastian**: some of these groups [sufferer support groups] are you know helpful but equally I find them very frustrating sometimes … I saw a lot of misunderstanding and it's like Brexit I think people have very strong opinions of what it is

3.4. Theme 2: Managing Day-To-Day With an Illness That Can Be Debilitating and Unpredictable

This theme covers the ongoing struggle of managing daily activities in the context of an illness that participants described as debilitating and unpredictable. The lack of certainty around when and how symptoms fluctuate undermined a sense of control, and often left participants thinking about if and how they will manage to keep up with day-to-day activities. Overall, this was associated with feelings of anxiety, and a reduction in activities, particularly social activities. There were also reports that continuing to search for explanation helped to keep hope, and gradually learn what helps. This was typically highly personalised, and closely connected with how they were making sense of CP/CPPS.

3.4.1. Some Days I Can't Do Anything

CP/CPPS was described by participants as, on occasion, completely overwhelming and significantly disruptive to daily life. This included descriptions of finding it hard to concentrate, feeling extremely fatigued, cancelling plans, taking time off work, staying at home, and staying in bed. Some participants conceptualised these moments as "flare-ups." And it was often felt that there was nothing they could do to "make a difference" and reported that these periods felt out of control.

> **Harry:** In a flare up sleep is your respite so you don't want to ever get up maybe that is exaggerating (.) err (.) but yeah you don't want to get up

> **Bob:** there are times where the pain is so bad or whatever when just not well or I’m tired or whatever, and it is kind of like there is not much point in doing anything else just I’m just out of it you know

> **Jeremy:** no matter how you sit or how you lie it is just <u>aching</u> … I was in tears you know because you can’t make any difference it was just pain

As Harry and Filip describe below, flare-ups were often very distressing, and accompanied by catastrophic thoughts relating to how bad it might get, and if it would pass.

> **Harry:** when it flares up again you always think well is this the time when it comes and stays forever and never goes away and you know (.) and no matter how many times you go through a flare up it never makes it easier to deal with the next one because you think what if I am wrong what if it doesn’t go away and it just carries on every day and that is when you think you can’t live with pain that is eight or nine out of ten every day for the rest of your life that is just not a life worth living so you get into that kind of thought pattern and the longer it goes on a flare up the more you think this isn’t going away and you catastrophise

> **Filip**: sometimes you get a flare-up and you think is there going to be one day where I can’t keep it together and I’m going to have to go home and I might be in bed for a few days and then the other side of it is where does it go does it lead into incontinence

3.4.2. <u>It’s Hard to Predict So I’m Always Thinking What If?</u>

Participants of this study explained that a hard to predict pattern of fluctuating and changeable symptoms, left them perpetually fearful of symptoms worsening. This resulted in evaluating actions and activities against hypothesised counterfactuals such as ‘what if I feel worse?’ and ‘what if I can’t cope?’ This framed CP/CPPS as pervasive, making it hard to forget about, even during moments of relative amelioration. A consequence of this was moderation of activity (particularly social activity) and some participants reported feeling vulnerable even when physical symptoms were not present, making it hard for them to live in the moment.

> **Callum**: my mind was saying ‘well you can’t sit down on that chair over there’ or anywhere I went so if I did have the courage to leave the house my mind would automatically think ‘okay where is the nearest toilet’ and ‘I only have 20 minutes before I need the toilet again’ (laughs) and ‘oh I can’t have that coffee because I’m going to be out of it for 4 days’ and ‘did they actually put decaf in my coffee’ (laughs) all these little things … so the pain just made me see life a whole different kind of way

> **Bob:** I feel as though I live in a cloud kind of sort of thing, the things that you question (.) you question things not in terms of should I be doing that but in a kind of covert way but it’s kind of like you kind of temper everything

Sebastian and Jeremy personified CP/CPPS as a menacing character, lurking in the background with the power to disrupt activities that they perceive to be important, and/or valued. Participants often felt vulnerable, and over time, this was described as contributing toward a reduction in activities, and undermining future planning.

> **Jeremy:** it disrupts everything you want to do there's no (.) even if you want to do something that you enjoy doing you got that thing in the background going ‘ah I’m just gonna make your life hard so you won’t enjoy what you're doing’ so you know you won't go to the cinema because an hour or two hours to sit in the cinema just won't (sigh) bother you know (.) because you can't concentrate on that you know

> **Sebastian:** it [CP/CPPS] does make you feel less secure and it feels very precarious because dealing with pain at the time and erm (.) not

> knowing when a flare-up is going to come and when it is going to hit you if it hits at a time when you need to be concentrating it can knock your whole world away

As Jeremy and Callum touch on in the excerpt above, sitting was a concern, and used to demonstrate CP/CPPS's pervasiveness, and the disruption to daily life. Filip also spoke about how he reduced travel for work, in order to moderate long journeys involving sitting, explaining that he felt thankful he had a workplace where he could be flexible with his schedule, and concerned that if he tried to get a new job it might be difficult to moderate sitting in this way.

3.4.3. Searching for "Answers" as a Way of Keeping Hope and Learning What Helps

This subtheme interrelates with Theme 1, particularly the subtheme 'looking for alternative explanations' (section 3.3.5). It covers how managing day-to-day was supported by an ongoing search for "answers." This was described as important for keeping hope, and through this process participants reflected that over time they gradually learned what they find helpful for relieving suffering, which made it easier to manage day-to-day. It also has a connection with 'finding someone who listens' as this person could be influential in supporting this process (section 3.5.3).

> **Filip:** the way I just coped with the turbulence of it was to stay focused and try and read and soak up as much information as I could looking for forums and support groups and things I wasn't erm (..) what's the word (.) I wasn't as hopeless as (..) I was hoping (.) I knew there would be some way out of it I didn't let myself go way down into a spiral of depression

The "way(s) out" that participants found were diverse and included understanding CP/CPPS in relation to muscle tension, stress and anxiety, undetected persistent bacteria, personal histories, thought processes, and to some extent patterns of behaviour. As Harry described when finding explanations that made sense to him, participants often experienced a positive impact on mood, and a sense of control.

> **Harry:** I started to read more about pain and how it arises and so on and the fact that pain can be referred and chronic pain exists even when there is nothing there and here is why and you know you start to as you learn more about it you become more empowered and you think you understand it better and I think it gives you more hope to deal with it and the hope that one day it might go away whereas before it was like this is never going to go away there is no doctor out there who can help me

Underlying this was often the hope it might be “cured”, but alongside this was also a process of exploration and experimentation, through which participants gradually learnt what could be helpful them. Again, this was highly varied and personalised, including diet restrictions, medication and medical intervention, meditation, philosophical concepts (stoicism and pragmaticism), exercise, stretching, prostate massage, hot bathes, hot water bottles, distraction. Some participants described how CP/CPPS had become more manageable over time, with varying degrees of improvement. Matt and Sebastian spoke of experiencing years when they “almost forgot” about CP/CPPS, and felt they had “recovered”. However, it was emphasised that given the unpredictable nature of the illness, this was a slow and tenuous process of “trial and error”, during which they teased out from available information what was helpful *for them*.

> **Jeremy:** it's taken that long a time for me it's not a quick turnaround and I know things now that will set it off (.) so you sort of learn again what sets it off … it becomes a sort of management thing really

> **Filip:** the next three years err trial and error different things so I tried different physiotherapists I had a go at things like complimentary therapies acupuncture I knew things that sparked it off like yoga I used to like yoga quite a lot but I worked out that a lot of deep stretching seemed to impact it so the next three years were kind of trial and error just trying

> to find out what worked what didn't and then the last three years on the whole (.) I haven't had a great summer actually but on the whole the last three years the gaps between flare-ups having been getting longer so I am feeling a lot happier

It was also reflected that activities that relieved stress or had a positive impact on their mood where helpful. Callum and Bob, for example, both spoke about exercise, but as mentioned above the specific activities were varied.

> **Callum:** when I first (..) started to exercise I kind of found like a way in which to release my (..) I didn't see it at the time I just saw it as a means to get not necessarily get fit but to get my mind off symptoms and things like that and then also the realisation that exercise had a massive impact on how I felt and how I felt about myself

Some of the strategies also involved considerable personal investment, and eliciting the support of valued others (professionals, partners, other sufferers). Sebastian described multiple trips abroad to have medical intervention that was not available in the UK. Liam described deciding to take early retirement in support of lifestyle changes he believed to be helpful. And Callum described investing heavily in competitive sports which aligned with the concept of stoicism that he had found helpful.

> **Liam:** it's good now that I don't have to worry about work and I think that has got a lot to do with the condition is the stress and the anxiety (.) now I don't have those stresses so I've started fishing I've started archery try to go for long walks quite a lot (.) just trying to destress

Although as Bob highlights attempts at managing day-to-day are often against the backdrop of seeking "control", and ultimately hoping that the symptoms will disappear altogether.

> **Bob:** I also need, in my head, sort of to like think in terms of erm (.) what's the deal with this pain whose going to be in charge okay it's not going to go, I know it's not going to go, erm (.) but then I should have a sense of what that relationship is and that it is my relationship not pain's relationship… **Researcher:** What would it mean to you for you to be in charge of pain? Do you think that it is the case? **Bob:** Really what that would mean is it's not there (laughs) I defeat it

3.5. Theme 3: Sociality and Isolation

This theme represents participant's experiences navigating how to be in social contexts, which involved intimate, social, and professional relationships. Participants were cautious about how others might respond or perceive them, and efforts were often taken to conceal illness. Ideas of masculinity were identified as influential, and linked with feelings of shame. Participants of this study also described experiences in which they felt others were dismissive of their suffering, which appeared to reinforce a sense of shame, and isolation. Relationships in which they could speak openly, and did not fear being negatively judged, were highly valued. Intimate relationships were found to be different to other relationships, as participants described their partners being implicated by their proximity over time. They were however, often accompanied by feelings of guilt, which also related to ideas of masculinity.

3.5.1. Withdrawal From Social Activities

Participants described withdrawal from social activities, explaining that managing social interactions in addition to pain was particularly challenging. This included description of a loss of interest in socialising, as well as worrying that they would feel uncomfortable, find it stressful, and be distracted by CP/CPPS symptoms. This was influenced by expectations that they had of themselves, regarding how they 'should' be in social contexts and concerns that they may not "cope". This had the impact of actual physical separation from others, which for some participants negatively affected their confidence, mood, and ability to sustain relationships.

> **Harry:** [it has] never been a problem for me to make friends but keeping them is a problem and I guess there are also aspects of unreliability in the sense that if I go through bad periods then I don't want to socialise and then you lose confidence with people

As Bob touches on below, this was influenced by ideas of how they should be when they socialise (e.g. actively and visibly engaging in discussion and enjoying themselves).

> **Bob:** if I haven't got the energy … I just sort of kind of sort switch off erm so I think if I'm actually going out (.) I would just actually be sat there in the pub (laughs) kind of, I haven't got much energy, I've made it here, that is good enough, but I'll be thinking that's not good enough really you're kind of like, it's like anybody really isn't it, if you go out you're going out because of interaction of socialising and if someone is sat there not taking part it's a bit of a downer on things sort of so I'd so probably I'd (.) I'd feel uncomfortable

3.5.2. Shame and Stigma

It was often difficult to speak with others about CP/CPPS, and illness was largely concealed. In particular participants reported feelings of embarrassment and shame for experiencing illness that affected the pelvic region, and their emotional wellbeing. These feelings appeared to be shaped by ideas of masculinity. There was also fear that they would be stigmatised, or that their experiences would be dismissed, which were justified by recounting occasions when they felt ignored and misunderstood, or found others to be uncomfortable or dismissive. Participants also referenced the lack of public profile and resources for CP/CPPS as a barrier to reducing shame and stigma.

Some participants described how they have found it embarrassing or socially inappropriate to speak about symptoms, so they tended to avoid the subject.

> **Harry:** as opposed to saying 'I get migraines that will knock me out for a few days' you wouldn't be afraid to tell someone that it's not

> embarrassing so it [CP/CPPS] is in a very embarrassing part of the body which makes you not want to tell anyone which makes interacting with them difficult particularly when you have got a problem when you are in pain
>
> **Sebastian:** you're hiding it from people because of course you're not going to say I've got a lot of discomfort down there I'm constantly dribbling you know even though it's a tiny amount of discharge it is just it was horrific but you become so low that you stop engaging with people and you stray more into the depression realm

In particular, participants reported fears that others wouldn't understand, or they may be stigmatised, and that this was connected to issues of masculinity. This resulted in continuing to perform roles at work, and in social settings, as if they were not experiencing pain. In Harry's case he also felt fearful that his work may "find out" that his productivity is sometimes affected by chronic illness.

> **Callum:** I found it particularly hard to open up to a male for some reason because I kind of felt like they wouldn't understand how it can just dictate your day erm (.) and somehow by being vulnerable about it it was making me less manly to a guy

Participants justified these fears by recounting negative experiences in which their suffering was dismissed or ignored. When this happened in medical contexts, it was described as being especially hurtful.

> **Filip:** I think the last appointment I had at that particular time at that GP surgery it was interesting I was in tears and shaking and in a complete mess but they just failed to see that

Bob in particular recounted multiple occasions when he felt he was not listened to, which instigated a long complaint process through which he felt further ignored, damaging his trust in the health service, and leaving him feeling as if his experience was “unwanted.” Bob described how during this process his suffering increased, which he connected to feeling actively ignored.

> **Bob:** I was starting to get very emotional about things sort of erm (.) the pain wasn’t just emanating from my pelvis it was kind of like I was getting into an emotional state where physically and emotionally it hurts just sitting and I couldn’t help but think this was a reaction to another statement another process where people weren’t listening

This was placed within a wider context in which participants felt “no-one is interested”, and CP/CPPS did not have sufficient “prestige” to garner attention or resources that might help to address shame and stigma, contrasting it with prostate cancer, and women’s pelvic pain. As a result, if participants did disclose experiences with another person, they were burdened with trying to explain the condition, describing how others had rarely heard of it, and that there was no easy was to share information. Raising the profile of CP/CPPS was felt to be important to participants (and often motivation for their participation in this study), and this was described as relating to concerns that participants often felt isolated and ashamed, which perpetuated a silence around the condition, and hampered opportunities to improve support.

> **Liam:** you know there may be other people who have this condition but they just don’t want to admit it because again I think it’s a male thing ‘oh I want to be big and butch and strong’ you know you don’t talk about your bits

3.5.3. Finding Someone Who Listens

In the context of feeling ignored and isolated, experiences with professionals (often sought privately), such as physiotherapists, psychological therapists, and doctors where they felt listened to, were highly valued. Alongside professionals there were also accounts of participants speaking with other sufferers, and with their partners. Participants spoke about how having regular contact with a person who they perceived to have some expertise, and showed interest in their experience (giving examples of active listening, sharing resources, following-up over time with ideas they discussed), made them feel valued and supported. Positive experiences were often described as holistic, collaborative, and individualised, helping participants with their search for understanding alongside managing the day-to-day, and ultimately making them feel less alone (connecting with subtheme ‘searching for answers as a way of keeping home and learning what helps’ section 3.4.3).

> **Bob:** she [a physiotherapist] was (.) committed to what she was doing and (..) it was my situation that she was interested in… **Researcher:** And how did that make you feel that idea that she was committed? **Bob:** it sounds like a cliché that I mattered (laughs) I mean that is what came into my head but actually that reduces it to a cliché really but I think (.) I think it was the issue (.) is that sort of if you use the metaphor of a journey really that we were that there was a direction we were going somewhere, she (.) wasn’t going through the motions she was actually someone who was going somewhere and wanted to take you somewhere in terms of your symptoms and so on err (.) I mean interestingly I’m just trying to think of a different word to listening really

> **Filip:** I got erm 12 sessions with a pelvic pain physiotherapist and the lady the physiotherapist she was more experienced with female pelvic pain … but she did look into [male pelvic pain] a lot more and she knew understood the experiences I’d read about and err she came up with 12 sessions of quite good deep pelvic stretches that I could breathe into and coping just coping with chronic pain which on its own was really really useful and I still do a lot of today err and just quietening down my pelvis and my nerves and just understanding that was a really powerful experience just someone who would sit with you and talk about different things you could try and say you know you are not going mad

As Callum explains, regarding speaking with a counsellor, some of these relationships were significant for challenging stigma and shame. This was experienced as initially frightening but later empowering.

> **Callum:** I do remember the first session and I hadn't opened up to a guy about it before I hadn't even told my father so opening up in that first session that actually I had something that was chronic nature and in my pelvic region I was just like 'ah shit I can't believe I'm about to do to this'

Some participants reported how important it was for them to know that there was someone they can return to, that support was available, which appeared to be emotionally containing. Similarly, other participants described how helpful it was that they could meet someone who they had developed a relationship with, so they did not have to try and re-explain their experiences.

> **Liam:** now I go every three months just when I feel things a wee bit tight tender he does his magic which isn't very pleasant erm … **Researcher:** What was it about that support his intervention that you found so helpful? **Liam:** I remember the very first time I went there I burst into tears and he just said 'Liam as long as you've not got cancer in your prostate as long as it's not bacterial I will be able to help' and he said 'you are not alone in this'

Jeremy and Filip also spoke about getting support from other individual sufferers, one of which was female. In these examples, knowing that they weren't alone, sharing information about what to expect, and having the sense that they were "understood", and could "empathise" with each other, was considered helpful.

3.5.4. "Strain" and Proximity in Intimate Relationships

CP/CPPS was described as closely affecting intimate relationships. The impact it had on sexual activity was reported to be one of the most difficult aspects of living with CP/CPPS. Participants described concern about their relationships being put under “strain”, whilst some reported increased closeness, describing their partners as a source of vital emotional support.

Sexual activity was reported to be affected, however this varied across the sample and included pain during and after sex, sexual dysfunction, premature ejaculation, lower libido, fear of triggering pain, and anxiety around sexual performance. Some of these experiences were considered side effects of various medications. The consequences of these difficulties were described as loss of confidence and reduced sexual activity. This was often (although not always) considered to be problematic, with participants describing feelings of guilt, anger, and shame.

The following excerpt from Jeremy, a participant who described the impact on sexual activity as the most difficult part of living with CP/CPPS, gives insight into factors influencing a reduction in sexual activity, and the influence of ideas about what he “should” be able to do.

> **Jeremy:** you know in sort of recent times I don't even feel the urge to have sex just because I sort of (.) know it's going to be rubbish (laughs) I don't mean that in a … it's just (.) I'm not going to be able to function properly because something will hurt there's always that worry in the back of your mind that it's like ‘oh’ (sigh) it's almost becomes too much bother … and then I sort of you feel frustrated for your partner then because it's like well I can't do what I should do you know should be able to do so yeah it's certainly the long-term effects for me in that sense have been (..) sort of depressing

Accounts of guilt, anger, and shame that this aspect of their lives was affected were shared. This was influenced by expectations that they held around sexual expression in relation to “being a man”, which shaped concerns that they were “inadequate” or might be disappointing their partners.

> **Bob:** I suppose I’m a traditional sort of man I sort of feel sometimes I am letting Judith down which is sad that I should think that (laughs) but I guess it’s there (..) erm erm (.) I don’t (.) and Judith isn’t very vocal about sex and it isn’t that I am but she is less vocal than I am sort of thing erm (.) but yeah I do have that thought but I wish I didn’t have that thought

> **Callum:** I was experiencing a lot of shame because we weren’t able to have sex so there was none of that intimate connection that could be formed from it … I felt like erm (..) I was less of a man because of it

Some participants described fears that sexual dysfunction might result in infertility or relationship breakdown. Matt reflected that prior to his current relationship, he had turned down relationships due to anxiety about sexual performance. Sebastian also described feeling “terrified” of new sexual relationships as he believed that it would aggravate symptoms (which he believed originated from a sexual transmitted disease).

> **Sebastian:** sexuality is a huge part of you and when that is (.) really screwed up then (.) it it’s psychologically it is hugely harmful because you end up (.) thinking ‘well I can’t have a normal sexual relationship’ so that part is removed so ‘I’ll be on my own’

In addition to sexual difficulties, it was reported that partners were also negatively affected by their mood changes (irritability, anxiety, low mood were named), and introspection, which was associated with feelings of guilt.

> **Matt:** it made me a more difficult person to be around because I think you take it out on your loved one when you are anxious or stressed about something

> **Jeremy:** I think when it was bad I certainly was a lot grumpier but I think a lot of people are if you're if you're in constant pain you tend to be your sort of fuse gets a bit shorter and erm (.) you know you're a bit of a bit

> more easily niggled by things. **Researcher:** and what kind of impact did that have? **Jeremy:** Just you know just mostly short temper with my wife and that you know I'd be a bit cross about it

Feelings of guilt associated with the perceived impact on partners suggested that participants held ideas about sharing distress or asking for support. Callum, who reported a relationship breakdown, described that he was worried his partner was "bearing the weight" of his struggle, and that this had influenced the end of his relationship.

> **Callum:** I kind of felt like well would it be easier to let her go and then she doesn't have to bear the weight of my struggle and I don't have to worry about her as much because of it

Although participants of this study described their relationships as being under "strain," it was also reported that partners were often a source of validation and understanding, particularly when symptoms are overwhelming, and daily functioning impaired.

> **Jeremy:** having a partner who is understanding that that's a problem helps and just generally being sympathetic about you know (..) that you don't look ill (.) there's nothing physically wrong with you you know I'm a perfectly healthy looking person and can do things but (.) I'm constantly in agony

> **Liam:** if anything it has bought us closer (.) emotionally (.) together you know she has been great you know at the beginning I didn't think (.) she thought 'oh Liam you've only got pain in your balls' but it's taken a couple of years for her to see … that pain in that area has produced tears at times so I think she then did realise

Filip who is the only participant in a same-sex relationship, reported beliefs that a same-sex partner may have facilitated further closeness.

Filip: you end up being a lot closer because you end up talking about that kind of stuff and you get home and the end of the day and I can talk openly in terms of ‘how was it today how was it when you went for a wee’ and things like that err yeah I have got a kind of because I’m in a same sex relationship we have got the same sort of bits it might not be so easy in a straight relationship

4. DISCUSSION

This chapter summarises and discusses the research findings in relation to the research aims and questions, and relevant literature and theory. Implications for clinical practice and further research are considered, and a critical evaluation provided.

4.1. Summary of Findings

The aim of this study was to increase understanding of men's experiences of living with CP/CPPS. In particular it aimed to explore how men describe and make sense of their experiences, and to consider how this may influence and be influenced by interpersonal and social contexts. Three themes and 12 subthemes were constructed through analysis of the data.

The first theme: 'trying to make sense of what is "wrong" in a "spiral of confusion,"' described how persistent symptoms that include pain, urinary difficulties and sexual dysfunction can challenge assumptions about health, and be experienced as shocking and confusing, particularly during the earlier part of the illness. Medicine was expected to provide answers, and confusion was amplified by unsatisfactory information and explanation, regarding cause and treatment for CP/CPPS. In this uncertainty, men worried that they would be denied further support and that physical symptoms were indicative of life-threatening illness. With no effective treatment available, men also struggled to make sense of what it meant for their future.

The second theme: 'managing day-to-day with an illness that can be debilitating and unpredictable,' described the significant disruption to daily life that CP/CPPS can cause, particularly during flare-ups. Uncertainty regarding when a flare-up could occur, and how disruptive it might be, undermined any internal sense of control, fueling a constant evaluation of men's behaviour, and a subsequent reduction in activity. Keeping hope by continuing to search for an explanation (and treatment) for CP/CPPS, was described as an important way to get through the day-to-day. Some men described how they had found helpful ways of managing, which, as a way of helping them to make sense of their illness, connected with aspects of the first theme. This was also influenced by supportive relationships.

The third theme: ‘sociality and isolation,’ represents how CP/CPPS can be an isolating illness, with men reporting withdrawal from social activities, and describing barriers to speaking with others about their suffering (if they shared it at all). This was associated with feelings of shame and stigma, which were influenced by ideas many held around masculinity. Men described how these feelings were reinforced by negative experiences when they perceived that they had been ignored or dismissed. Intimate relationships were found to differ from other social relations due to physical proximity over time. This context was also influenced by ideas of what it means to be a man, and can be accompanied by feelings of shame, guilt, and anger about the “strain” that men considered CP/CPPS to have on their intimate relationships. Generally speaking, the responses of others were found to be particularly important, and relationships where men felt listened to and supported were highly valued.

Some of the themes and subthemes connected to each other (see Appendix N for thematic map). There is a bidirectional relationship for example between ‘searching for “answers” as a way of keeping hope and learning what helps’ and ‘looking for alternative explanations.’ And ‘finding someone who listens’ also connected with the subtheme of ‘searching for answers as a way of keeping hope and learning what helps.’ Overall, there was also a sense of experiences changing over time, which suggests that there may be a developmental trajectory.

4.2. Revisiting the Research Questions

Two questions were constructed to support the aim of increasing understanding of men’s experiences of living with CP/CPPS, and particularly how these interacted with interpersonal contexts. The first question was ‘how do men experience living with CP/CPPS?’ And the second question was ‘how have their experiences of CP/CPPS influenced and been influenced by social contexts and relationships?’ Whilst taking these into consideration, findings will now be discussed in relation to literature outlined in the introduction.

4.3. Discussion of Findings in Relation to Existing Literature

The results are discussed primarily with other qualitative studies, however due to the sparsity of qualitative studies in this area quantitative studies are also included where it was deemed relevant (with the methodology made explicit).

The early period of illness, particularly onset and persistence of symptoms, was described as alarming and confusing, with symptoms challenging assumptions about health, illness, and age; and men struggling to make sense of what is “wrong.” Similar to other studies it was found that men seek support within medical systems (primarily GPs, urologists), and these experiences were often recounted as unsatisfying and unhelpful (Jonsson & Hedelin, 2008; Wood et al., 2017).

There was resemblance with the studies by Wood et al. (2017), and Jonsson and Hedelin (2008), in that men felt their suffering was not taken seriously and that there was a lack of clear and consistent information about the diagnostic process, diagnosis of CP/CPPS, and the pathway of care and treatment, adding to distress. In the current study, this was also connected with men’s expectations of medicine to provide the “answer,” which would enable symptoms to be resolved and illness to be short-lived. The idea that, at present, medicine does not have effective treatments for CP/CPPS, was extremely frightening, with men overwhelmed by what this means for them, and how this might affect their future. Jonsson and Hedelin (2008) reported a similar point in their study, noting that their sample described experiences are much less difficult to endure if a cause can be identified, and if there is hope that symptoms, even if chronic, won’t last forever. In this study, unsatisfied with the information and support provided, men sought alternative explanations, which was complicated by the heterogeneity of experiences between sufferers, and the variety of unsubstantiated explanations.

Jonsson and Hedelin (2008) also reported that interactions with medical professionals were influenced by fears that symptoms indicated life-threatening disease. A similar fear was described by participants in the current study, with men often citing a worry that it might be, or lead to, cancer, despite tests ruling this out. For this sample, fears were amplified by a context of uncertainty and the process of medical investigations that excluded rather than confirmed. This also converges with a quantitative study by Mehik et al. (2001), who found that 17% of men in a sample of 1832 reported fears that prostatitis indicated prostate cancer, although this was not described by participants in other qualitative studies (Hatchett et al., 2009; Wood et al., 2017).

Jonsson and Hedelin (2008) found that straightforward information about the diagnosis and ‘probable’ cause, had a reassuring effect, and supported acceptance of the situation. This was similarly described in Wood’s (2015) personal account, with an emphasis on transparency around the current limitations of medical understanding and what support might be available. Positive experiences in this study were unfortunately far-and-few between, however helpful experiences included when emotional impact of their experiences were acknowledged (and support for this discussed).

Overall this highlights the significance of medical contexts as a space in which men look for support in making sense and managing symptoms. It draws attention to the power that healthcare professionals hold in terms of validating experiences and helping men to feel reassured and supported, whilst they navigate the loss of expectations that illness will be short-lived and what this means for their futures.

Similar to other studies, it was found that men experienced periods when their daily functioning was significantly disrupted (Hatchett et al., 2009; Jonsson &

Hedelin, 2008; Wood et al., 2017). In the current study, men described symptoms as variable over time, or “flaring-up,” and that during these moments it could be difficult to concentrate, and men felt extremely fatigued, low in mood, and feared they may never end. During these moments’ men withdrew from daily tasks and activities. Similar findings were reported by other qualitative studies, however the issue of fatigue featured more prominently for the participants in the studies by Hatchett et al. (2009), and Jonsson and Hedelin (2008), who linked this to sleep disrupted by pain and frequent urination.

Similar to one of the themes in the study by Wood et al. (2017) (‘the erratic nature of CP/CPPS: debilitating, elusive, and fluctuating’), the unpredictable nature of when flare-ups may occur was undermined a sense of control over the illness. In the current study this was described by participants as feeling fearful of symptoms worsening and driving a constant evaluation of actions and activities against hypothesised counterfactuals such as ‘what if I feel worse’ and ‘what if I can’t cope.’ Likewise, Jonsson and Hedelin (2008) reported that within their sample many lived in constant fear of recurrence. Moderating activity was often used as a way of managing this, and in the current study adjustments to sitting was a commonly cited issue, demonstrating the ubiquity of potential triggers that may aggravate symptoms. Sitting as a common issue was similar to findings by Wood et al. (2017), and also in the quantitative study by Turner et al. (2006) who reported that 41.6% of their sample perceived sitting as aggravating pain. Moderating activities also holds some similarity to the study by Hatchett et al. (2009) who reported role limitations in particular at work due to fear that they may not be able to function because of symptoms, and that as a result there was a loss of career progression. It also has some similarities to Jonsson and Hedelin (2008) who described using routines and restrained behaviour to help manage feelings of anxiety that symptoms may flare-up and impede functioning. Overall this indicates a high burden for men in terms of adjusting their own behaviour, rather than informing others of needs and asking for adjustments.

Findings of the current study suggest that one way of managing day-to-day was by searching for “answers.” This was often driven by the hope that CP/CPPS could be “controlled”, and that a sense of agency would return to men’s lives. This was similar to findings by Jonsson and Hedelin (2008), and Wood et al. (2017), who both reported that men used hope and positive thinking, which was important in fighting feelings of despair. In the current study, searching for “answers” was also found to propel a process of experimentation and learning what helps. Many of the participants described how they felt that CP/CPPS had become more manageable over time (with varying degrees of change), but that the journey to this was often slow and tenuous. What participants found helpful varied widely, however central to the process was the development of individualised explanations, that provided personal meaning and understanding. This was a similar finding to a study by Wood et al. (2017), who reported that a search for meaning as a means to positively manage the illness.

The variety of strategies shared by participants in the current study was also similar to Wood et al. (2017), and to the quantitative study by Turner et al. (2006) which reported a wide-ranging and contradictory approaches between participants. Points of particular similarities to other studies in the description of helpful strategies were changing body positions (i.e. movement), and recreational activities that had a positive effect on mood (Jonsson & Hedelin, 2008; Wood et al., 2017).

Importantly the current study has highlighted that this is extremely individualised, and also that seeking strategies to help manage CP/CPPS can come as considerable personal cost with some men describing financial and personal investment. It was also found in the current study that there was considerable value perceived from consistent relationships which fostered this learning, and where they could speak openly. This shares some similarity with Wood et al. (2017) who reported the importance of sharing their experiences with someone who cares. However, this study has extended this understanding as it found professionals (often sought privately) such as physiotherapists, psychologist therapists (and for one participant a urologist) who were perceived to have some expertise and commitment to the subject, were important highly relationships. Partners were also named as important sources of support, and other sufferers. However, findings differed slightly as less of the participants in this study reported connecting with other sufferers via online platforms, when compared with Wood et al. (2017), and two participants in this study described support from other individual sufferers (although not through online platforms). It is unclear why this difference emerged; however, this study's findings suggest that there was something important in having consistent and individualised support that was available over time, and it may be that this was less feasible from online forums or support groups. Perhaps importantly, in this study, some men described finding it frightening to hear experiences of symptoms worsening over time, reporting that variation between sufferers was a barrier to shared understanding, and that it can add to confusion when there are conflicting opinions about what can help.

This study shares similarities with Hatchett et al. (2009), and Jonsson and Hedelin (2008), in finding that mood was influential regarding men's withdrawal from social contexts. These studies described 'sudden' changes in mood, whereas men in the current study described "not being in the mood," a loss of interest, and difficulty concentrating, suggesting that social relations are considered particularly demanding whilst experiencing CP/CPPS. The consequences of social withdrawal were increased isolation and lowered self-confidence, which was similarly found in a study by Jonsson and Hedelin (2008).

Other studies reported that reduced social contact was also associated with men's desire to hide their illness (Hatchett et al., 2009; Jonsson & Hedelin, 2008). This study also found that men often concealed symptoms in social and/or work settings, with men describing feelings of shame, and fear of stigma, as barriers to sharing their experiences, which perpetuated feelings of difference and isolation. Shame was similarly reported in other qualitative studies (Jonsson & Hedelin, 2008; Wood et al., 2017). Jonsson and Hedelin (2008) identified that shame was influential in men "performing" roles at work, and in social contexts, in a way that does not suggest they are experiencing illness. This was reported to include displays of strength, suggestive of social constructs relating to masculinity. Findings of this study were similar, with men describing fear of stigma if they spoke about CP/CPPS or displayed emotional vulnerability, and that this was relevant to both work and social contexts. This suggests that CP/CPPS indicates to men a loss of social status and value (Gilbert, 2003; Gilbert & Andrews, 1998).

This study was also similar to Wood et al.'s (2017) study in finding that feelings of shame were reinforced by invalidating and dismissive responses, and that when men experienced responses like this from medical professionals they could be particularly hurtful. This was extended in particular by the connection, in this sample, to a wider context in which men experienced others as "not interested," evidenced by examples of other people not listening or dismissing experiences, but also a lack of research, pathways of care, specialised services, and lack of presence in the media or in public campaigns. Seen together this was understood as reinforcing the idea that CP/CPPS is inherently shameful or of less value, and perpetuating an ongoing silence and lack of supportive spaces (Gilbert & Andrews, 1998).

Participants in the current study drew attention to the importance of intimate relationships in their experiences of CP/CPPS. Men's accounts supported previous quantitative studies that indicated changed sexual functioning, which can include pain during and after sex, sexual dysfunction, premature ejaculation, lower libido, fear of triggering pain and overall reduced sexual activity (Aubin et al., 2008; Hatchett et al., 2009; K. Smith et al., 2007). This research has contributed more understanding in relation to this, with findings highlighting that men not only worry about pain during, or after sex, but worry about failing to meet expectations of themselves "as a man", or having a "normal" sexual relationship, which give rise to feelings of guilt, anger and shame about the disruption to sexual activity, and a perceived negative impact on their relationships. This has some similarities to a study by Hatchett et al. (2009) who found 25% of their sample reported feeling "unable to fulfill role as intimate partner", which was linked to changed sexual activity and feelings of guilt as well as 'letting partners down.'

Quantitative research into CP/CPPS has found that low mood and stress are implicated in sexual functioning (Aubin et al., 2008; K. Smith et al., 2007). Concerns regarding mood was also described in the qualitative study by Jonsson and Hedelin (2008) whey they reported sexual dysfunction negatively affecting mood, and that men felt mood had a negative effect on relationships (new and established). Similarly, Hatchett et al. (2009) reported mood changes, particularly low mood, irritability, and frustration as felt to negatively impact family relations. The current study extends current understanding of this, as participants described a perception that relationships were placed under "strain," and men experienced feelings of guilt, anger and shame that was shaped by ideas of masculinity, and not wanting to "burden" partners.

The response of partners was also important in shaping experiences. In this sample they were often described as sources of important support and validation, and some men described an "increased closeness" developing as a result of such close and extended proximity. This might help to give some insight into quantitative studies that have found, when compared to control groups, that despite increased sexual function, men with CP/CPPS and their partners, do not necessarily have significant differences in overall couple satisfaction or relationship functioning (Aubin et al., 2008; K. Smith et al., 2007).

4.4. Links to Theory

4.4.1. Adapting the Self to Illness

It has been argued that chronic illness presents significant challenges to a sense of self, and the unity between how the self and body is experienced (Bury, 1982; Charmaz, 1995, 2002). The onset of illness is considered by Bury (1982) to be a biographical disruption that raises existential questions, initiating a process of self-reconstruction and reorganisation. Whereas, Charmaz (2002) argues that it is a threat to the self, and brings into consciousness "habits" of thinking, feelings, and actions that had hitherto typically been conducted without reflection. Participants in the current described shock and confusion, particularly during the earlier stages of illness when CP/CPPS is unexpected, and assumptions relating to participants body, age, and ability are being challenged or violated. Furthermore, physical changes and altered daily functioning are not just about limits to activity but also influenced what it meant for who they were in relationships, at work, and who they imagined they might be in the future. In line with models of the self, CP/CPPS appears to present considerable challenge to a man's sense of self.

Bio-medicine, Bury (1982) argues, is the primary framework in which people look to make sense of illness, and is one which can separate illness from the self through the "objectivity of disease" (p. 173). Furthermore, he argues that the medical model of disease situates the patient in a passive position, and subjugates their experiences of illness and how this links to their context, beliefs and values (Bury, 2001; Frank, 1995). In the current study all men sought answers from medicine, and Bury's ideas can help understand the high expectations men had for medicine to provide "answers", and the despair and disappointment that was felt when biomedical understandings were unable to provide either clear explanations or effective treatments. It also suggests that many of the men held initial assumptions about illness that were in line with Parson's (1951) concept of the 'sick role,' which assumes recovery from illness, successful medical intervention, and positions patients as passive (Parsons, 1951). This is similar to what Frank (1995) refers to as 'the restitution narrative,' which situates illness as temporary and separate to the self.

This study suggests that in the context of current medical limitations and the lack of sufficient explanation, men are driven to take a more active role, searching for explanation and meaning that is helpful to them. According to Frank (1995) this can be considered 'post-colonial', in that it involves finding stories of their illness that moves beyond the dominant medical narrative. The accounts of men in this study give a sense of a journey overtime, during which men carry the burden of finding ways to make sense of their experiences and through which the importance of learning from experiential knowledge (rather than knowledge provided by others) is heightened. Using Charmaz's (2002) theory of self in chronic illness, it is argued that it is through this learning that new habits and ways of thinking about themselves enable an adjustment of the self to incorporate illness. Furthermore, she argues that through this transformation people begin to give up notions of "victory" over illness. The men in the current study however described a journey often underscored by hope of "defeat," suggesting that men may hold onto hopes of recovering their old 'well' self. Furthermore, men spoke about concealing illness, and refraining from social contexts due to fears that they may not "cope" in fulfilling expected roles. Charmaz (2002) argues that social situations as important in shaping self-concept, however findings of the current study would indicate that there are few spaces where men can develop this, and that through withdrawal and concealment men may be looking for ways to hold onto illness as temporary; indicating that accepting a changed self (and future self) is extremely difficult.

According to Frank (1995) and Charmaz (1994), men can reveal how much the self has accommodated illness by the way in which they frame it. In this study, for example, some participants portrayed CP/CPPS as a menace, intruding into valued aspects of their lives, akin to an intrusive presence. Whilst one participant spoke about it as an attack, likening CP/CPPS to an "enemy", he reflected that he had come to see it as "an opportunity" for personal growth. Frank (1993), and Charmaz (1994) argue that it is in the articulation of experiences that people define and make sense of suffering and begin to reconcile it in relation to the self (Frank, 1995). Thus Frank's 'chaos narrative' underscores the way illness is seen as a malign and meaningless intrusion, giving way (for some) to a 'quest narrative', whereby positive meaning is found within the illness itself, rather than the possibility of escape from the illness. However, this also brings up the question of where men have the opportunity to articulate their experiences given the current study reporting it is largely concealed or dismissed.

Both Bury (1982), and Charmaz (2001; 1995) also reflect on how a process of adjusting the self in illness occurs slowly over time. They suggest it is typically accompanied by alterations to behaviour and lifestyle, and Charmaz (1995) argued that it involves phases of ignoring, minimising, struggling against, and eventually reconciling with the illness. As highlighted above, this study's findings suggest that achieving a state of reconciliation or 'acceptance' in ACT terms, is extremely difficult. Findings in this study also stress that this involves not just the individual, but is influenced by – and draws upon – support from others, for example adjusting ways of showing vulnerability and being intimate in relationships, of continuing work, or finding and committing to regular appointments with a supportive professional.

Using Bury (1982) model, this can be considered akin to the final stage of his model which involves the mobilisation of resources (following earlier stages of disruption of assumptions and behaviours, and fundamental rethinking of self-concept), and highlights that this is a stage where disparity in resources can become prominent. The findings of this study suggest that this was the case. Filip described being "lucky" to secure financial support from his partner's private healthcare so he could afford to see a physiotherapist, and Liam reflected that he was unsure how he would have been able to take early retirement if he was not in a secure financial position. This is a particularly salient point because it suggests men's experiences of CP/CPPS can be influenced by socio-economic inequality, limiting access to support, and flexibility of lifestyles or work environments.

4.4.2. Gender and Masculinity

Masculinity refers to the social processes that construct what it means to be a man (Connell, 2009). Findings in this study indicate that ideas pertaining to gender and masculinity were implicated in men's interpersonal relationships, and often associated with feelings of shame, guilt and anger. This suggests that CP/CPPS challenges ideas of what it means 'to be a man', and that masculinity is a socio-cultural framework that men draw upon, and feel diminished by.

Charmaz (1994) argues that when views of the body are predicated on ideas relating to hegemonic masculinity (e.g. strong personal control, invincibility, high functioning), then a struggle with chronic illness is likely to be heightened, as it presents additional dilemmas for identity. It is hard to say, based on these findings how much this theory holds true, particularly as masculinities are increasingly multiple and subject to changing socio-cultural contexts (Connell, 2009; Courtenay, 2000a). However, the results suggest that ideas of masculinity and gender were particularly pertinent to sexual functioning and intimate relationships, as well as concerns around displaying emotional or physical vulnerability in front of others. In particular regarding intimate relationships, men struggled with fears about challenges to sexual performance placing a "strain" on their relationships, in spite of partners reportedly not expressing dissatisfaction.

With Charmaz 's (1994) theory of identity dilemma, it can be argued that intimate relationships become an "elaborate dance", where men struggle with increased dependence on partners in relation to internalised masculine constructs that are at odds with reliance on other people (p. 280). This can help to understand men's concerns around "strain," and as a dynamic social interaction, and how the other responds is likely to be influential in terms of reinforcing or challenging constructs of gender (Connell, 2000).

4.5. Implications

4.5.1. Medical Consultations

Findings indicate that medical consultations often with GPs or urologists are critical contexts in which men look to make sense of an illness that can be experienced as disruptive, shameful, and a threat to their sense of self. Two main implications are drawn from the findings: improving communication and attending to emotional distress.

4.5.1.1. Improving communication

It is likely to be helpful for men provided with clear and consistent information about the process of referrals and investigations, the exclusion of other illness, and the trials of medication. In particular providing reassurance that their experiences are being taken seriously is likely to be helpful in addressing fears of not being believed or that they may be denied further support. Additionally, the current study highlighted expectations from men that medicine can resolve symptoms, and conversations introducing CP/CPPS may be extremely distressing and heighten feelings of despair, including suicidality. It would therefore be of benefit to introduce this as early as possible in the process, be transparent with men about current understanding, but also foster hope with positive examples of living well with CP/CPPS and discussing avenues for support. This should also align with the biopsychosocial approach to understanding illness, currently recommended by guidelines for the management of CP/CPPS (Engel, 1977; Engeler et al., 2020).

This recommendation relies on clinicians themselves having a good understanding of CP/CPPS, being reflexive about their own position, and how this may impact interactions and men's experiences (Engeler et al., 2020; Toye, Seers, & Barker, 2017). It is therefore recommended that CP/CPPS is included within medical CPD training programmes and that this includes learning about CP/CPPS from an integrated perspective, reflecting on their own position, and practicing communication skills.

4.5.1.2. Attending to emotional distress

Attending to individual psychological and social difficulties, as well as physical concerns, of the client is implicated. This is in line with a biopsychosocial approach to understanding illness, currently recommended by guidelines for the management of CP/CPPS (Engel, 1977; Engeler et al., 2020). In particular, the current study found that men experience high levels of emotional distress, and that feelings of shame and stigma shaped by ideas of masculinity, may act as a barrier to sharing this with others. It would therefore be helpful for professionals to ensure that, in line with the biopsychosocial model, they are explicitly naming and validating emotional distress as part of CP/CPPS (Engel, 1977).

Psychological therapists are also increasingly situated in primary care services, and offering men access to this support at an early stage may be important not only in ensuring emotional needs are attended to, but also communicating that illness is more than physical and that emotional distress is valid and important (NHS England and NHS Improvement, 2018).

4.5.2. Interventions

4.5.2.1. Access to integrated care

Findings suggests that men have found holistic and individualised approaches to their wellbeing beneficial. As an initial tool, the UPOINT classification appears to be promising (Shoskes et al., 2010; Shoskes, Nickel, Rackley, & Pontari, 2009). This tool supports clinicians to explore CP/CPPS as a collection of experiences, so helps to create an individualised and multimodal approach, well suited to the heterogeneity of the condition (Shoskes et al., 2010, 2009). This arguably carries risk, however, in isolating aspects of men's experiences, which may be reductive for understanding men's experiences as a whole. It is therefore recommended that alongside the use of this tool, clinicians consider men's experiences, using ideas set out in the biopsychosocial model in which context and subjective meaning are integrated alongside biological factors (Engel, 1977).

In the UK, specialist pain management services are well suited to this as they provide access to a multidisciplinary approach and take an integrated approach to management of chronic pain that includes pharmacology, physiotherapy, psychology, and surgery (Faculty of Pain Medicine, 2015). It would therefore be of potential benefit for men to be supported in accessing specialist chronic pains services as soon as possible.

4.5.2.2. Making meaning and reconciling the self with CP/CPPS

Men in this study described experiences of being overwhelmed and confused by CP/CPPS. Improvement over time was linked to learning from experience, enabling men to make sense of the self with CP/CPPS, using personalised frameworks of understanding and meaning. Psychological interventions that provide men with space to explore what it means for them to live with CP/CPPS, to not ‘get well’ as may have been expected, could be helpful in supporting men to move towards a position of reconciliation (Charmaz, 1995; Frank, 1995). ACT, which focuses on accepting illness, and developing committed valued-based action, may be well suited to this (McCracken, 2015; McCracken & Vowles, 2014). Narrative practices, with an emphasis on supporting and witnessing the reauthoring of experiences, may be an approach that fits well with also (White & Epston, 1990). And existential therapies such as logotherapy which focuses on the exploration of meaning may also be helpful (Frankl, 2014).

4.5.2.3. Including systemic factors

The themes identified suggest men’s experiences are interrelated with their relationships, and wider social contexts. It may therefore be beneficial to widen the focus of interventions to address systemic factors. For example, this could include working with partners to address concerns about sexual intimacy, and feelings of guilt or shame. It may also consider tackling stigma associated with chronic illness and disability, and/or address the lack of public information and awareness around CP/CPPS. Systemic approaches are particularly well suited to situating ‘problems’ as residing between rather than within individuals, which may also help tackle internalised feelings of shame, and help to share the burden of chronic illness as a society (Dallos & Stedmon, 2014; Gilbert & Andrews, 1998)

4.5.2.4. Group programmes

Group programmes that draw on principles of ACT, and CBT, are well established in chronic pain services within the UK (Faculty of Pain Medicine, 2015; The British Pain Society, 2013). The sample in this study suggest that connecting with other sufferers can be experienced as supportive, but equally can be scary and confusing, due to the heterogeneity of experiences, and lack of shared understanding. It is therefore recommended that individual support is also offered if men do not want to join a group setting, however group programmes may provide a powerful context in which shame and stigma can be challenged. It may be that once men are able to share with a trusted individual, they will feel more comfortable sharing in a group context, and the wider world.

4.5.3. Future Research

A limitation of this research was the lack of diversity within the sample in terms of ethnicity, sexuality, and relationship status. It would be beneficial for future research to use samples that reflect diversity; and consider how these differences may intersect with experiences. There was some indication that socio-economic inequalities may be salient, which would benefit from further consideration. Given that this study found implications for intimate relationships, it may be helpful to conduct qualitative research into the experiences of partners (no qualitative research has done this to date). It may also be particularly useful to have future research consider how this affects men outside of long-term/committed relationships.

Medical stories were dominant in these findings; however, no research was found to explore clinician's experiences of working with men with CP/CPPS. It would therefore be helpful for future research to consider conducting research with clinicians involved in the care of men with CP/CPPS, to better understand their experiences. It would, in particular, be helpful to explore clinician's understandings of CP/CPPS, at what stage during the process of investigations and medication trials CP/CPPS is typically discussed, what attitudes they hold towards the condition, and how this might influence the overall process.

There is currently very minimal research evaluating outcomes of psychological and social interventions (Edwards et al., 2019; Tripp et al., 2011). It would be helpful for more research to be done in this area, and for there to be more specific information about the elements of psychological interventions that are effective and valued by participants.

Finally, I am aware that some men with CP/CPPS have identified themselves as 'cured', as this appears in non-empirical literature, and in the support groups (Astier, 2018; Parks, 2010). Research into the experiences of men who consider themselves to have recovered would be of interest, as this is not currently represented in the literature, and may help to provide useful insight in challenging the idea of CP/CPPS as a chronic condition.

4.6. Critical Evaluation

Critical evaluation involves the assessment of research in terms of quality, contribution and how successfully it answered the research questions. It can be done using a variety of different frameworks (Treharne & Riggs, 2015). Spencer and Ritchie's (2012) guiding principles were selected to guide this process of assessment as they draw heavily on pre-existing frameworks, and broadly defines criteria that aid informed judgment without being mechanistic.

4.6.1. Contribution

Contribution refers to a study's value in addressing gaps in the current evidence base, and advancing the development of theory, policy and practice (Spencer & Ritchie, 2012). This research has furthered understanding of men's experiences of living with CP/CPPS, and has helped to address the current deficit in qualitative research that considers men's experiences of living (with others) with CP/CPPS. It has conducted a detailed TA, exploring experiences from the perspective of men with CP/CPPS in the UK, which no other study has done. Furthermore, it gives nuanced insight into how this interacts with socio-cultural and inter-personal contexts, which was identified as failing to be considered in quantitative studies.

Given that a qualitative approach was adopted, the results are not intended to be generalisable to a wider population, but to provide vivid insight into a phenomenon (Levitt et al., 2017). Therefore, knowledge gained is specific to participants, time and cultural context. However, the exploratory nature of this research is valuable in terms of generating new avenues of understanding, future investigation, and implications for clinical practice. It is hoped that this is of value for improving the support available to men with CP/CPPS.

4.6.2. Credibility

Credibility was sought by triangulating the research process with the principal supervisor, who has conducted research in this area, and speaks as an expert by experience. Triangulation of the analysis was sought through sharing and discussing an excerpt of coded transcript, overview of initial codes, subthemes and themes, and thematic maps.

Credibility was also improved by involving men with CP/CPPS from the beginning of research project, in particular consulting on the focus of the research, and questions in the interview schedule (Treharne & Riggs, 2015). An overview of results is planned to be shared with participants and a support group for men with CP/CPPS, as a way of not only disseminating findings, but also checking resonance, and further investigating credibility.

Finally, credibility has sought to be demonstrated in the write-up of the findings, by using thick descriptions, backed up by excerpts, and then situating findings in relation to theory and empirical evidence. In addition to this, effort has been made to describe and present findings in a way that is clear and supports dissemination and the application of findings to practice (Nowell et al., 2017; Spencer & Ritchie, 2012).

4.6.3. Rigour and Transparency

Auditability of this research relates to the replicability of method (Spencer & Ritchie, 2012). The methodological process and any decisions taken in relation to this, have been shared in this report with the aim of being as transparent as possible. This is done for example in outlining in detail each stage of the process (section 2.4.1), providing extracts of coding (see Appendix K) and thematic maps to show process of developing themes (see Appendices L, M, N).

Justification and implications of choices relating to ontology, epistemology and methodology are outlined in the Methods chapter. Steps were taken to explain why TA was selected over other approaches, and to consider how it may influence outcomes. Decisions concerning participant information, inclusion and exclusion criteria, as well as the process of recruitment are also clearly explained. Finally, steps have been taken to ensure reflexivity, and transparency of this within the report, and will be addressed again in the following section.

4.6.4. Reflexivity

Reflexivity has been interwoven at every stage of the process with the use of a reflective diary as well as discussions with principal supervisor, and a TA supervision group. Reflexivity about the position of the researcher, and the methodology, are also shared in this report as a way of being transparent about their influence over findings.

4.6.4.1. Personal Reflexivity

Personal reflexivity is important in terms of continually observing and questioning how my own position may influence data; and taking steps to ensure that this is challenged so that results were as closely aligned to the emerging participant data as possible (Treharne & Riggs, 2015). A reflective diary was used to name my own thoughts and feelings after interviews, and these were also discussed with the principal supervisor, and in TA peer group (see Appendix O for reflective diary excerpt).

I was aware that as a heterosexual cis woman living without chronic illness, I have assumptions in relation to illness, sexuality and gender, that are likely to have influenced my findings. As a trainee clinical psychologist, I am aware that this may have influenced my analysis in terms of my being more attuned to psychological frameworks. Therefore, steps such as giving equal reading time to all texts, and discussing findings with the principal supervisor was important in attempting to address this. As a novice researcher I experienced doubt in my own abilities, particularly as I became aware of the responsibility of transforming data into codes, subthemes, and themes. This is likely to have influenced outcomes, and steps taken to overcome this were learning to trust in the process, and seeking support as and when needed.

In terms of the interviews themselves, I am aware that my background and manner in interviews will have influenced how participants answered questions. Interviews often were extremely detailed, feeling almost driven by some men, as if they urgently wanted to articulate their experiences to another person. Many of the participants at the end of the interviews spoke about how they had found it valuable to have been listened to without judgement, and this drew my attention towards their views of me as an interviewer. I reflected that this was potentially related to gender, and that I was perceived as less-threatening than if I had been male for example. I also reflected that it may also relate to my position as a novice researcher who is more comfortable in the role of a therapist, and therefore I tended to position my questions from a curious and empathetic stance which may have also contributed towards a particular gender stereotypes (Lefkowich, 2019). As the results indicate, accounts of difficult experiences with medical professionals were dominant, and therapists (psychological and physiotherapists) portrayed as more helpful. On reflection it is likely that the interviews were also influenced by their awareness of my own professional background.

4.6.4.2. Methodological Reflexivity

A critical realist position was adopted for this project. This assumed a reality to men’s experiences but also enabled sensitivity towards social, cultural and historical structures that shape meaning (Braun & Clarke, 2013; Willig, 2013). It was hoped that this would encourage findings that can have ‘real-world’ implications, and would fit well with the research aims and questions. Analysis was approached using an inductive TA, which aligned with an ‘empathetic’ interpretation of the data (Willig, 2017). This can be considered a strength in terms of being exploratory, and close to the data, but similarly a weakness in that outcomes are not as closely tied to the research questions as they may have been if a deductive approach had been adopted, and may fall short in terms of looking deeper into ‘hidden’ meanings. I also found TA may have been limiting in terms of conveying how experiences of CP/CPPS changed over time.

Qualitative methodology, and the use of individual interviews enabled flexibility in terms of remaining exploratory, and closely examining experience, perspective and meaning (Kvale, 1996; Rohleder & Lyons, 2015). Findings of the study indicate feelings of shame and fear of stigma can be barriers to speaking about illness, and supported the decision to use individual interviews, although individual interviews likely bought their own constraints, which are outlined in personal reflexivity.

Participants were recruited from a variety of forums over the internet. The methodology of interviews carried out either in person or on Skype allowed for men from across the UK to participate. Men were selected on a first-come-first-serve basis after having read an information sheet. This may have given advantage to men with access to internet and resources to respond quickly and engage in interviews. Eight participants was considered sufficient in providing meaning analysis and appropriate due to the significant level of detail shared during the interviews (Guest et al., 2006)

The sample represented a wide range of men in terms of duration of illness, and diversity of physical symptoms. A limitation of this study is that all participants identified as White, and it therefore does not provide insight into how ethnicity may intersect with experiences of living with CP/CPPS. There is minimal research that explores ethnic demographics of men with CP/CPPS, however quantitative studies that are available suggest that men across different ethnicities are affected, and that white men are no more likely than other ethnic groups to have a diagnosis of CP/CPPS (Cheah et al., 2003; McNaughton Collins et al., 1998). Furthermore, differences in sexuality and relationship status are not well represented within the sample, as all men reported being in committed relationships and seven of the eight participants identifying as heterosexual. Overall, this means that results may be biased towards White heteronormative men in relationships.

A strength of this study is the involvement of men with CP/CPPS throughout the project. Including experts by experience in the research project, as recommended by the National Institute for Health Research, is reported to have a number of benefits, and it is important from an ethical perspective for addressing issues of power in publicly funded research (Brinkmann & Kvale, 2017; Gradinger et al., 2015; UK Public Involvement Standards Development Partnership, 2019). The high level of motivation that participants in this research held, as a way of increasing awareness, challenging stigma, and instigating change was very inspirational, and in the future it would be important to further include men with CP/CPPS in research, potentially utilising participatory research approaches (Vaughen, 2015)

4.7. Final Summary

Through semi-structured interviews with eight men in the UK, this study provides insight into the experiences of living with CP/CPPS. The findings highlight that CP/CPPS can be a disruptive and debilitating illness, which is closely connected to relationships and social contexts. In particular it has called attention to how isolated men can feel, and the difficulties that can be faced in accessing support. A number of implications are outlined for clinical practice and research, which underscore how much needs to be done to alleviate suffering for men affected by CP/CPPS. Furthermore, this study highlights the importance of taking an integrated approach, and calls for a system-wide response.

Participants of this study often expressed hope that their participation would in some way help to raise awareness of CP/CPPS and improve the support available to other sufferers. It is hoped that this study will be successful in doing this, and that through the process of participating men felt heard and valued.

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6. APPENDICES

6.1. APPENDIX A: Responses and reflections from online consultation

Original Post on Social Media (September 2018):

Hello, my name is Sally and I am a trainee clinical psychologist currently completing a doctorate at the University of East London. Some of you may recall that (*name removed for anonymity)* posted about me joining the group, a few months ago. I am currently planning research that will involve speaking with men about their experience of CP/CPPS, in particular considering how this impacts relationships. I wanted to share this with the group whilst my research is still in development to ask, based on your experience, what kind of questions you think would be important to include? Many thanks, Sally

Responses:

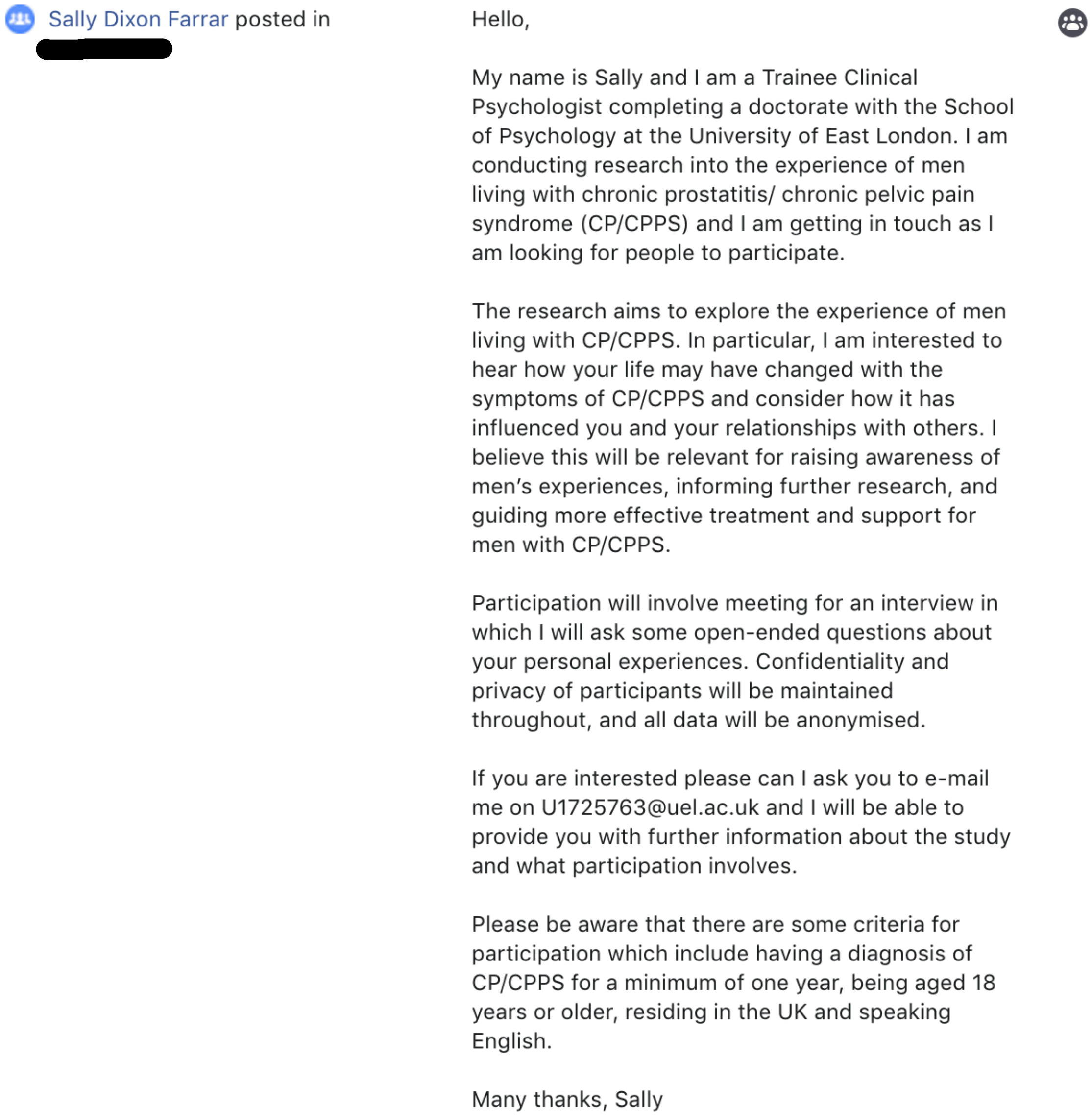
16 men responded. The following overview provides the main points from the discussion thread:

- It is likely to be difficult/ uncomfortable to ask about sex, but it is important to be ask as this is something that is affected by CP/CPPS and can be very distressing. Three men advised being direct with questions.
- Relationships and partners are placed under increased stress, with men saying that they find it hard to cry in front of women
- Establishing new intimate relationships can be particularly difficult when sex is difficult
- Other family relationships also perceived to suffer, with one man explaining he feels sad that he is not able to the father he would like to be
- Asking about urinary difficulties is also important
- It is important to conduct the research to raise awareness of CP/CPPS and also it would be helpful to have research that explores why it is neglected
- Two responses from partners saying they would be interested to help
- One negative and angry response saying that psychological research may assume psychological issues *cause* symptoms and arguing that research is needed in the field of biomedical science.

Excerpt from reflective log (November 2018):

Overall the feedback indicated that men were supportive of research and that they perceived a focus on relationships to be of value and could help to raise awareness of CP/CPPS. Most of the responses interpreted relationships as sexual and intimate relationships, which I wasn't expecting. It stimulated an awareness that sexual and intimate relationships may be particularly important, and I found it was interesting that there was feedback that this might be uncomfortable or difficult to speak about but that it was important to be direct and ask about sexual relationships. I was shocked about the one angry response. I understood that he felt frustrated that research was being proposed by a psychologist when he clearly perceived research resources would be better utilised by a biomedical discipline. He also assumed that my study would be making causal inferences. This makes me think it is really important to be transparent about my position and the aims of the research project. On reflection however this was only one response.

6.2. APPENDIX B: Recruitment Post on Online Forums



Sally Dixon Farrar posted in [redacted]

Hello,

My name is Sally and I am a Trainee Clinical Psychologist completing a doctorate with the School of Psychology at the University of East London. I am conducting research into the experience of men living with chronic prostatitis/ chronic pelvic pain syndrome (CP/CPPS) and I am getting in touch as I am looking for people to participate.

The research aims to explore the experience of men living with CP/CPPS. In particular, I am interested to hear how your life may have changed with the symptoms of CP/CPPS and consider how it has influenced you and your relationships with others. I believe this will be relevant for raising awareness of men's experiences, informing further research, and guiding more effective treatment and support for men with CP/CPPS.

Participation will involve meeting for an interview in which I will ask some open-ended questions about your personal experiences. Confidentiality and privacy of participants will be maintained throughout, and all data will be anonymised.

If you are interested please can I ask you to e-mail me on U1725763@uel.ac.uk and I will be able to provide you with further information about the study and what participation involves.

Please be aware that there are some criteria for participation which include having a diagnosis of CP/CPPS for a minimum of one year, being aged 18 years or older, residing in the UK and speaking English.

Many thanks, Sally

6.3. APPENDIX C: Information Sheet

University of East London
Pioneering Futures Since 1898

PARTICIPANT INFORMATION SHEET

Research Study Title: Towards an Understanding of Men's Experiences of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?
I am a Trainee Clinical Psychologist studying with the School of Psychology at the University of East London. I am studying for a doctorate in clinical psychology. As part of my studies I am conducting the research which you are being invited to participate in.

What is the research?
I am conducting research into the experiences of men with Chronic Prostatitis/ Chronic Pelvic Pain Syndrome (CP/CPPS). In particular, I am interested to hear how your life may have changed with the symptoms of CP/CPPS, and consider how it has influenced you and your relationships with others. With my research I aim to build a better understanding of the experiences of men with CP/CPPS as this is something which is currently missing in research.

My research has been approved by the School of Psychology Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?
You have been invited to participate in my research as you have received a diagnosis of CP/CPPS and I would like to hear how this may have influenced your life. It is important that you are aged 18 years or older, live in the UK, speak English, and that you have had the diagnosis for at least one year.

You will not be judged in any way and you will be treated with respect. Please be aware that you are free to decide whether or not to participate and should not feel coerced.

What will your participation involve?
If you are willing to participate this will involve a one-to-one semi-structured interview with myself. This is likely to involve me asking you a few open-ended

questions about your experience. It is my aim that this is conversational in nature, and I hope that this supports you to speak openly about your experience. An example question may be "how has your life changed since you were diagnosed with CP/CPPS?"
It is estimated that interviews will be between one hour and one and a half hours. Breaks will be encouraged and ahead of the interview we will discuss the setting of the interview to ensure it is a comfortable and private space.

The entire interview will be recorded using audio recording equipment.

In terms of reimbursement, all participants will be eligible for a £10 Amazon voucher. Some travel costs (within London) may also be eligible for reimbursement and this will be discussed on an individual basis.

Your taking part will be safe and confidential
Your privacy and safety will be respected at all times. All identifiable information will be anonymised in the process of transcribing. Only the researcher involved in the study will have access to identifying data, and all data will be stored on a secure database with password protection.

In the write-up of the research excerpts from interviews are likely to be presented, however all information will be anonymised ensuring that confidentiality is maintained.

During the interview you do not have to answer all questions asked and can stop participation at any time.

What will happen to the information that you provide?
The information that you share with me will go through a number of steps. These include:
a. Transcribing (during which data will be anonymised)
b. Analysis of information alongside information from other interviews
c. Write-up and dissemination
d. Post examination all audio files will be destroyed
e. Three years post examination all transcripts will be destroyed

Prior to the write-up anonymised information may be shared with the project supervisors (and the examination board if requested). After the write-up stage anonymised data will be included as part of presenting findings from the research. This will be shared with examiners and then stored on the UEL database.

Information from the write-up is also likely to be shared more widely in the form of academic journals and presentation. This will be entirely anonymous.

What if you want to withdraw?
You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Please be aware that approximately four weeks after the interview I will begin analysis, and after this

point it will no longer be possible to withdraw your data. However, during analysis all data will be completely anonymised.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

My name is Sally Farrar. My email address is U1725763@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Nick Wood, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: n.wood@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk)

6.4. APPENDIX D: Interview Schedule

Interview Schedule

The aim will be to encourage men to tell their story, and so questions will be used as a guide.

General prompts – can you tell me more about that? What was that like for you? How did that affect you? What did that mean to you?

A. Introduction and building rapport

- Review and provide copy of information sheet and answer any questions
- Check comfort of location and interview set-up (i.e. seating, preference to stand), and explain they can take a break or end the interview at any time
- Complete consent form

B. Demographic information

1. To begin with there are some demographic questions, please can I check your…
    a. Age?
    b. Sexuality?
    c. Relationship status?
    d. Gender identity?
    e. Ethnicity?

C. Experience

1. Can you tell me about when you first experienced symptoms of CPPS/CP and can you tell me what this was like for you? *(prompts: what was it that you first noticed? How did it initially affect you? What sense did you make of it?)*

2. How has your experience changed over time?

3. What has been the most difficult part of living with CP/CPPS?

4. What has helped?

5. How would you say your life has changed since having CP/CPPS? *(prompts: how has it changed or interfered with relationships, sex, social life, work, leisure?)*

6. What meaning do you make, if any, about having this illness?

7. Has it impacted how you view your future, and if so how?

D. Social contexts and relationships

8. Has CP/CPPS changed your relationships or how you relate to other people? And if so, how?

9. How much have you told (or not told) other people about your experience? What has influenced this, and what has this been like?

10. Has CP/CPPS changed your sexual or intimate relationships? If so, how and what has this been like for you?

E. Ending questions

11. What do you think need to happen that may make it easier to live with CP/CPPS? What would you like to happen?

12. Now that we've reached the end of the interview, is there anything that you feel we haven't covered, and that you want to share? Is there anything you hoped I would ask about that we haven't?

F. Debriefing

- Review and provide copy of debrief form
- Provide voucher/ travel expenses including completing relevant forms
- Ask how they found the interview process and any feedback to inform future interviews

G. Field notes

- Record reflections in diary, anything notable in terms of the interview dynamic, behaviour or participant characteristics

6.5. APPENDIX E: Consent Form

University of
East London
Pioneering Futures Since 1898

PARTICIPANT CONSENT FORM

Research Study Title: Towards an Understanding of Men's Experiences of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purpose of the research has been explained to me, and I have had the opportunity to discuss this and ask further questions about the study. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and in particular data from this research, will remain strictly confidential. Only the researcher involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………………….

Participant's Signature

………………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

………………………………………………………………………………………..

Researcher's Signature

…………………………………………………………………………………………

Date: ……………………..…….

6.6. APPENDIX F: Debrief Sheet

PARTICIPANT DEBRIEF SHEET

Research Study Title: Towards an Understanding of Men's Experiences of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)

Thank you for talking with me about your experiences and for contributing to this research. By doing this you have helped me to develop a better understanding of men's experiences of CP/CPPS. For an outline of how the information you have shared will be used, please refer to the information sheet. If you need another copy of this please let me know.

Sometimes people can find that speaking about their life experiences can bring up difficult feelings. If, after the interview has finished, you feel you would like to talk to someone then you can contact the Samaritans helpline on 116 123, 24 hours a day. You can also contact the CALM helpline, on 0800 585858, which is a mental health charity specifically for men or Prostate Cancer UK, on 0800 0748383 which is a charity that has specialist support for men with CP/CPPS.

If you have any further questions or decide that you do not want information you have shared with me to be used in the research study, please can I ask you to contact me or my supervisor. If possible, please try to contact me within three weeks.

My name is Sally Farrar. My email address is U1725763@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Dr Nick Wood, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: n.wood@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk)

6.7. APPENDIX G: Ethical Approval

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER:	**Matthew Jones-Chesters**
SUPERVISOR:	**Nicholas Woods**
STUDENT:	**Sally Farrar**

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: TBC

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

APPROVED

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Matthew Jones Chesters

Date: 22 March 2019

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

6.8. APPENDIX H: Approved Amendments to Ethics Application

UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

Name of applicant:	Sally Farrar
Programme of study:	Doctorate in Clinical Psychology
Title of research:	Towards an Understanding of Men's Experience of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)
Name of supervisor:	Dr Nicholas Wood

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Participants will be offered a £10 Amazon voucher and reimbursement of travel costs within London, in line with what is available through the School of Psychology.	This is to facilitate recruitment and is considered necessary from an ethical perspective in terms of valuing the contribution of participants who will be required to take time out of their lives to talk with me about a personal subject.
Research questions slightly amended, previously they were: *How has life changed for men since having CP/CPPS?* *How has their experience of CP/CPPS influenced and been influenced by social contexts and relationships?* *How does has this overlapped with issues of identity and masculinity?* Now they are: *How do men experience living with CP/CPPS?* *How has their experience of CP/CPPS influenced and been influenced by social contexts and relationships?*	Due to continued development of project, including consultation with service users regarding the focus.

Please tick	**YES**	**NO**
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student’s signature (please type your name): Sally Farrar

Date: 20th October 2019

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Tim Lomas

Date: 21.10.19

UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

Name of applicant: Sally Farrar
Programme of study: Doctorate in Clinical Psychology
Title of research: Towards an Understanding of Men's Experience of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)
Name of supervisor: Dr Nicholas Wood

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Title of study in all appendices was slightly incorrect. The proposed amendment is to ensure that this is all consistent and in line with the title of the study which is: Towards an Understanding of Men's Experience of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS). Previously the name was accidentally inverted (i.e. CPPS/CP rather than CP/CPPS).	To ensure consistency of the title throughout all documents

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name): Sally Farrar

Date: 7th February 2020

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Tim Lomas

Date: 7.2.20

UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

Name of applicant: Sally Farrar
Programme of study: Doctorate in Clinical Psychology
Title of research: Towards an Understanding of Men's Experiences of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)
Name of supervisor: Dr Nicholas Wood

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Title of the study to be changed due to grammatical error. The proposed amendment is to ensure that the title is: **Towards an Understanding of Men's Experiences of Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)**	To ensure consistency of the title throughout all documents

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name): Sally Farrar

Date: 16th March 2020

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	Yes	
Comments		

Reviewer: Tim Lomas

Date: 16.3.20

6.9. APPENDIX I: Transcription key

Symbols	*Meaning*
(.)	Short pause
(..)	Long pause
..	Incomprehensible word
(example)	Description of behaviour such as laughing or sighing
<u>example</u>	Emphasis on word through intonation
[example]	Description of notable interruption such as taking a break

6.10. APPENDIX J: Reflective Log Excerpt from Process of Transcribing

Participant 2: At the end of writing up this participant's account I was really struck by the level of ***concealment*** *he described, there was a lot of* ***shame and embarrassment*** *for him. He worked in a competitive work environment and described fear of stigma and that others would not understand the illness that he himself struggled to understand and that it might affect his emotional wellbeing. He also* ***struggled with making sense of his symptoms*** *particularly as he said he could not identify any reliable pattern to fluctuations. His was a* ***long journey of medical investigations*** *which he described as* ***disheartening****. There was a quote that I felt captured his frustration about lack of any biomedical marker "there has never been any evidence of what is going on apart from my own experience." He also spoke about the* ***heterogeneity*** *of CP/CPPS as making it difficult to find useful information from online forums. Writing it out for transcription, it reminded me how difficult it must have been for him to speak so openly given his reports of concealing it from so many of his friends, colleagues and family.*

6.11. APPENDIX K: Excerpt from Coded Transcript

scary diagnosis of just get on with it or we will cut you about a bit and see what happens so

R: And what was it like for that initial period? Can you tell me a bit about how it impacted you?

F: I think I was terrified because there was no support from the GP they washed their hands of me I think they thought I was a bit of a hypochondriac or it was in my head a little bit the urologist went straight through their normal route which was just reading some kind of flow chart erm no mention of other potential things that can cause pelvic pain nerve damage you know anything else that I've read about since and it was very kind of that is the end of it I'm going to have to put up with the pain or have some kind of operation which is probably going to leave me in more pain or no sex life erm or might be incontinent so it was very stressful I was still very stressed there was a lot going on in my life I was struggling at work because I was finding it hard to sit down for long periods and I was also traveling a lot the actual things of being able to (..) stay at work and the pressures of pain building and I also had all sorts of things going through my head that perhaps I wouldn't be able to cope with normal day-to-day life so it is very hard to avoid catastrophic thinking at those points so you kind of go a little bit into meltdown yeah (.) it was scary times it was probably one of the hardest things the hardest period of my life in 43 years t's pretty scary times

Sally FARRAR
Feeling terrified with no support
Feeling dismissed in terms of severity 'I think they thought I was a hypochondriac or it was in my head a little bit'

Sally FARRAR
No information about potential causes
Left with sense of putting up with it of have operation

Sally FARRAR
Stressful; struggling to sit down for long period of time impacting work

Sally FARRAR
Feeling scared
Catastrophic thoughts

R: And what kind of impact did the symptoms have for you? I know it is very different for different people

F: Yeah so sitting a lot of burning I think some people say it is like sciatica kind of feelings the main thing was keeping sat down for long periods and then at the end of a long day being sat down at the office all day terribly red and feeling hot legs hot pelvis I dreaded going to the loo because it was like weeing glass sometimes erm yeah it was just the general discomfort going to bed feeling absolutely miserable knowing that erm I would wake up the next morning with the same feeling so just sort of no escape the only escape is you know if you took and I still do occasionally if you took strongest over the counter medication you can get like co-codamol or something and I also started drinking a bit to try and numb the pain not a lot you know but at the weekends I would certainly drink to try and escape a little bit

Sally FARRAR
Sitting as aggravating
Urination as painful

Sally FARRAR
Feeling that there is no escape and fearing waking up in pain

Sally FARRAR
Painkiller to escaping pain

Sally FARRAR
Alcohol as a way of escaping pain

R: And how did you make sense of what was happening at this point?

F: Erm my first reaction was of disbelief and that started me erm reading a lot I like reading and researching so I did start buying books looking for self-help anything from the first books I got were pretty useless but things like going to (removed for anonymity) and buying herbal remedies and I was meditating I was grasping as straws thinking there has got to be a way out there has got to be someone who has gone through it erm (..) so it was just treading water in a way trying to make sense of it but it was hard to remember it was a very grey time I managed to cope for a couple of months and then I went on honeymoon to (removed for anonymity) and because the stress was building up when I was there I didn't have a breakdown but I kind of went into a bit of a meltdown with the pain I had almost like anxiety symptoms you know struggling to go out and about in touristy places erm I managed to see a GP there that was actually very sympathetic and said 'I've seen this before' and he immediately put me onto a low dose of antidepressants and said 'this will

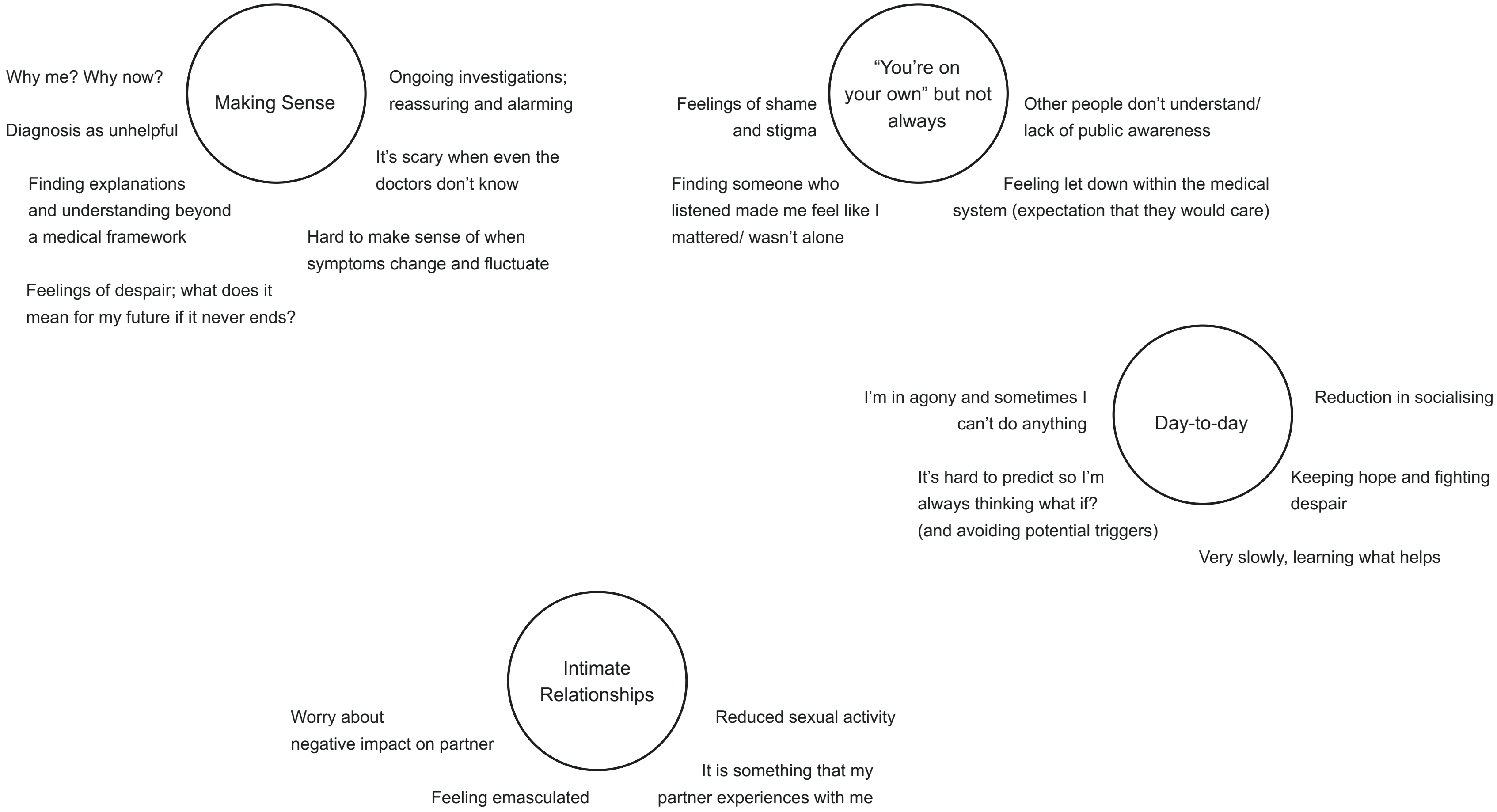
Sally FARRAR
First reaction is disbelief

Sally FARRAR
Desperately seeking a solution/ relief

Sally FARRAR
Anxiety and stress

Sally FARRAR
Antidepressants to help with mood

6.12. APPENDIX L: Intermediate Map 1



Making Sense

- Why me? Why now?
- Diagnosis as unhelpful
- Finding explanations and understanding beyond a medical framework
- Feelings of despair; what does it mean for my future if it never ends?
- Ongoing investigations; reassuring and alarming
- It’s scary when even the doctors don’t know
- Hard to make sense of when symptoms change and fluctuate

“You’re on your own” but not always

- Feelings of shame and stigma
- Finding someone who listened made me feel like I mattered/ wasn’t alone
- Other people don’t understand/ lack of public awareness
- Feeling let down within the medical system (expectation that they would care)

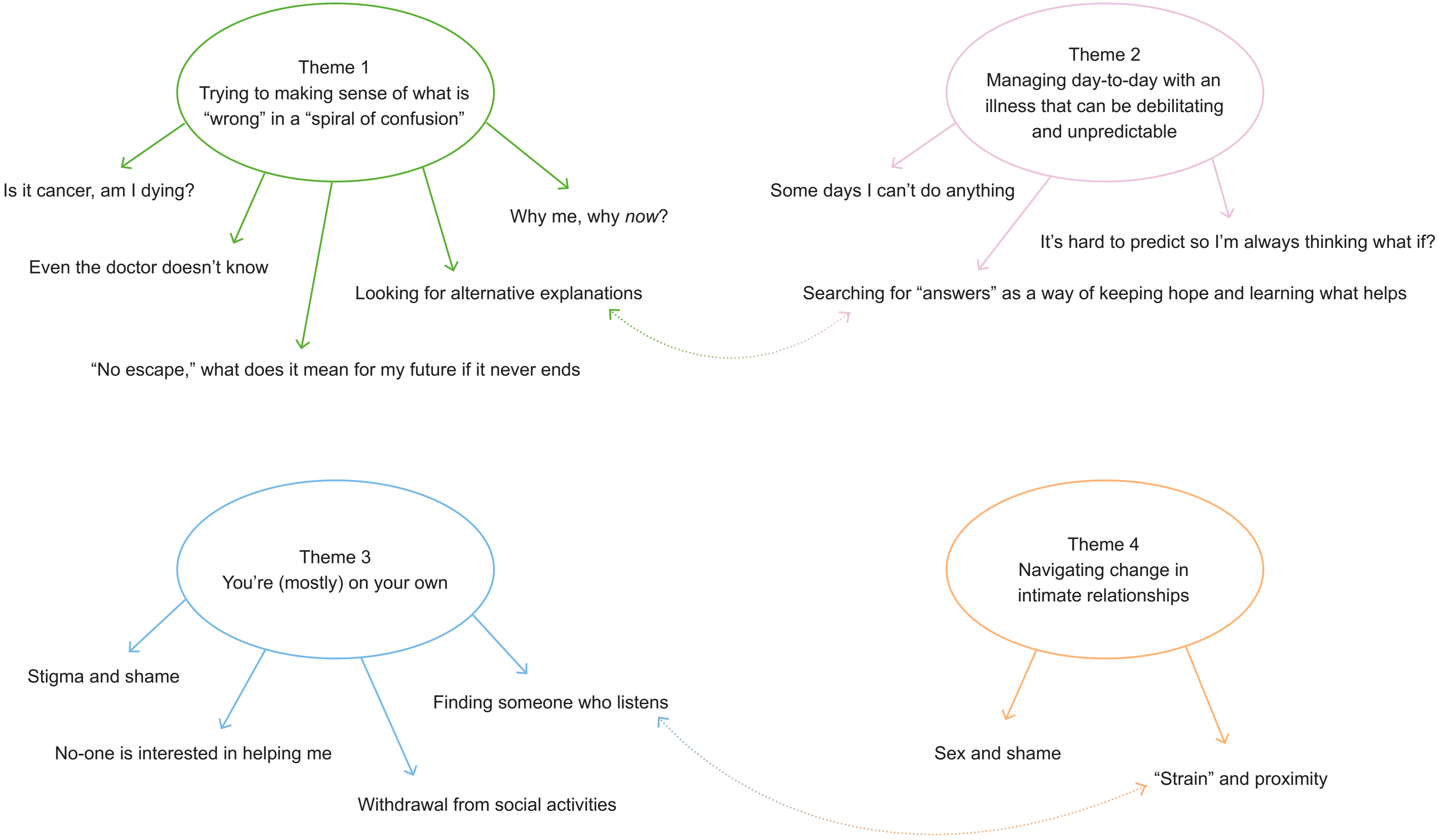
Day-to-day

- I’m in agony and sometimes I can’t do anything
- It’s hard to predict so I’m always thinking what if? (and avoiding potential triggers)
- Reduction in socialising
- Keeping hope and fighting despair
- Very slowly, learning what helps

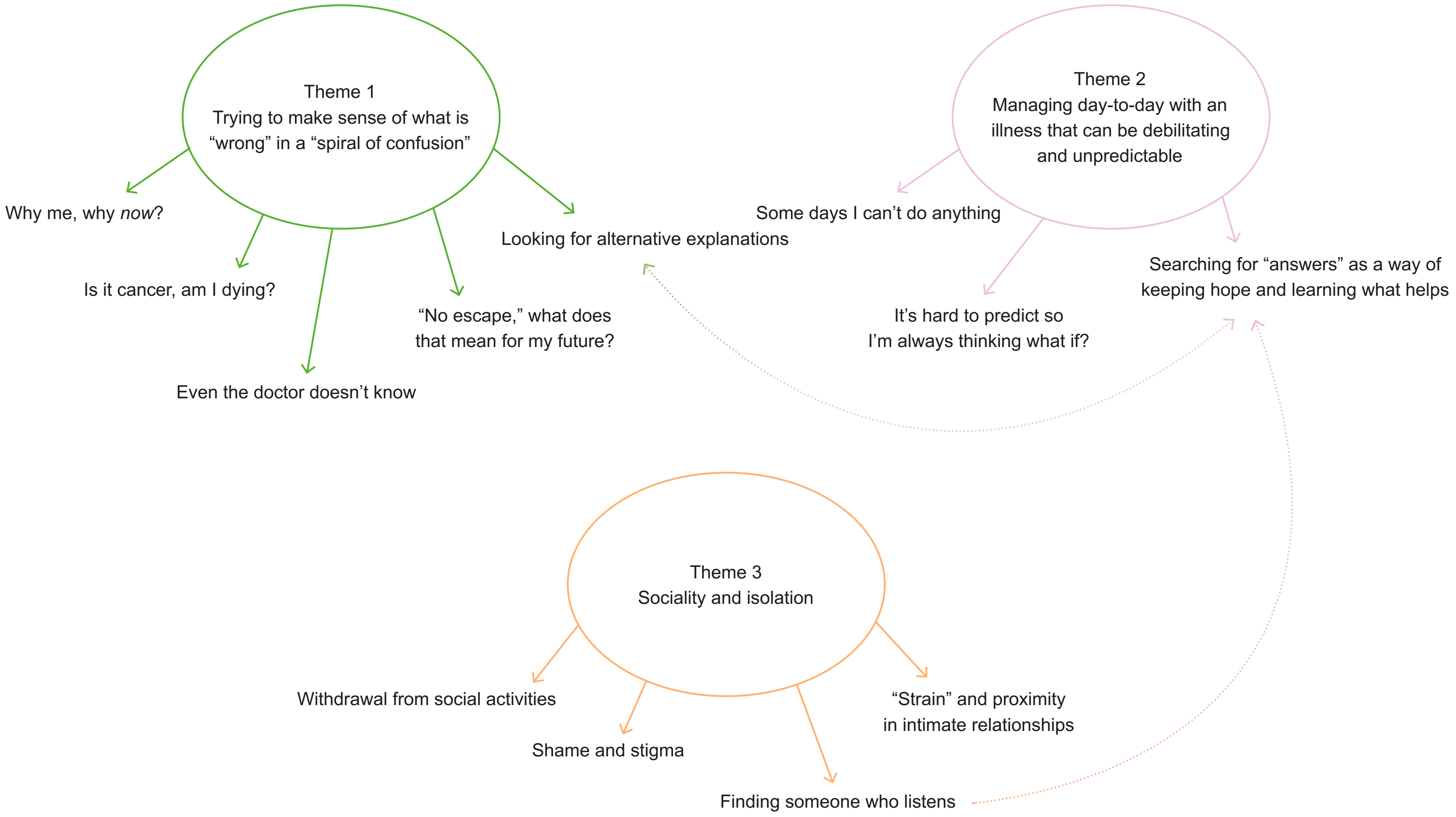
Intimate Relationships

- Worry about negative impact on partner
- Feeling emasculated
- Reduced sexual activity
- It is something that my partner experiences with me

6.13. APPENDIX M: Intermediate Map 2



6.14. APPENDIX N: Final Thematic Map



6.15. APPENDIX O: Reflective Diary Excerpt during Interviews

This was the first interview and so I noticed I felt apprehensive before starting, concerned that the participant may find it difficult to speak openly about his experience. The interview was also over Skype and I was happy to find that this did not seem to inhibit rapport building, although was probably made easier due to a good internet connection and he was in his study to ensure privacy during the interview.

During the interview itself I felt that he spoke freely, although I occasionally prompted to meaning as I thought he sometimes appeared to be slightly more reserved in sharing what it meant for him and how he felt. I think that this was also influenced by my own nervousness and not wanting to 'miss' anything, so in the future whilst it may be helpful to prompt for meaning I might want to pause a little more before I decide to ask a follow-up question. I wonder if I was being a bit pushy sometimes by asking him how he felt and think that this may be influenced by my experiences of conducting therapy rather than research. I also stumbled over the questions sometimes, making them more long-winded than they need to be, something to be improved on in the next interview.

In terms of the subjects that came up, I noticed that I felt a strong sense of empathy for him and it reminded me of the client who I had met before starting this project. In particular I felt moments of particular empathy when he described his disappointment that medicine could not "fix" CP/CPPS and when he explained that CP/CPPS doesn't let you enjoy what he would previously have considered enjoyable activities, and this made me feel incredibly sad. Sometimes I was struck by his positive demeanour which seemed at odds with what he was describing, and part of his account was about how he finds it important to keep positive, and in some ways I wondered if this was also influencing the way in which he spoke about some of his experiences. I noticed that during the interview I was self-conscious and nervous asking about relationships and sexual intimacy. I think I was more nervous than he was. He was actually very direct in naming changes to sexual activity as the hardest part of his experience. This has made me aware of my own beliefs about what is *socially appropriate to speak about, and his response has actually given me more confidence to be direct in asking about this. I didn't find gender differences or dynamics to be readily apparent in this interview. Although on reflection I wonder if he used more ambiguous language when referring to genitalia and sexual functioning because I was female. I noticed I was very much in listening position, and wondered a little if this related not only to being a researcher but was also influenced by power dynamics of me as a younger woman listening to an older white man.*

Finally, at the end of the interview we took a little longer with the ending. It felt appropriate to wind down as we had spoken about a lot of very personal subjects. He was really keen to tell me how he was motivated to participate in the study as a way of improving support for other sufferers and raising awareness. He was also curious about my motivation. I found myself feeling very inspired by this, and also a sense of responsibility to help, which was a difficult feeling to be left with and I think may relate to having heard how much he felt support was lacking.

Points to take forward for the next interview:
- *Pausing more before questions, and giving more time to participant*
- *Not being afraid to ask about sexual relationships*
- *Being aware that interviews may elicit in me a strong sense of empathy and wanting to provide support*
- *Useful to have the time to wind down*
- *Themes in terms of content: sexual relationship particularly difficult, shock and struggle associated with finding out medicine can't "fix" it and it may be forever, keeping hope/ positive thinking as a way of managing, sense of journey over time.*