

Running head: *CP/CPPS*

Positioning, telling and performing a male illness: Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)

Nicholas Wood (1), Annum Quereshi (2), and Fahim Mughal (3).

¹University of East London

²University of Hertfordshire

³University of Hertfordshire

Word count (exc. figures/tables): 5998

*Requests for reprints should be addressed to Dr. Nicholas Wood, 22 Victoria Road, London, England, U.K.: nick45wood@gmail.com

Background:

Chronic Prostatitis/ Chronic Pelvic Pain Syndrome (CP/CPPS) is a chronic health condition affecting men of all ages with an estimated worldwide prevalence of between 2.7 and up to 16% (Krieger, Ross, & Riley, 2002; Marszalek et al., 2008). CP/CPPS is a debilitating syndrome characterized by persistent discomfort in the lower pelvic area including the bladder area, testicles, and penis. Symptoms can be severe and include painful and frequent urination as well as difficult or painful ejaculation. The cause of the condition is unknown (Nickel, Berger, & Pontari, 2006).

Despite the significant prevalence of CP/CPPS, until relatively recently, there was a concerning lack of research. With current uncertainty around the aetiology of CP/CPPS, definitive effective treatment of the condition has yet to be determined (Dimitrakov, Kaplan, Kroenke, Jackson, & Freeman, 2006; Engeler, et al., 2017).

One of the difficulties with Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS) is that it is a diagnosis by exclusion, i.e. there is an initial search for other medical possibilities that generate huge anxieties, such as (prostate) cancer. Although the past ten years have seen a relative increase in the research into CP/CPPS (Nickel et al., 2006; Nickel, Mullins, & Tripp, 2008), there is still a relative shortage of resources for men suffering from CP/CPPS, with the former British charity, Prostate Action (2010), referring to it as ‘the forgotten prostate disease.’ As mentioned, CP/CPPS has a high prevalence rate, with a recent European study suggesting it accounts for a quarter of all male urology consultations in the UK (Marszalek et al., 2008). Given treatment limitations, first port of call is usually an anti-biotic, even if there is no clear indication of a bacterial infection (Nickel et al., 2008).

One of the characteristics of CP/CPPS is that it appears to be a ‘heterogeneous’ condition, i.e. it has unique and individual variations, even if there is some core degree of overlap which

taps into the overall syndrome of CP/CPSP. The National Institute of Health in America have classified CP/CPSP in the four categories below, with a 'Chronic Prostatitis Symptom Index' to assess severity and impact on functioning (Vasan, 2012).

- I. Acute Prostatitis <3 months
- II. Chronic bacterial prostatitis >3 months; infection identified
- III. Chronic prostatitis/chronic pelvic pain syndrome – no identified infection
- IV. Asymptomatic inflammatory prostatitis

The Category III (CP/CPSP), with no identified infection, constitutes approximately 95% of all cases and is thus by far the most common 'type' of this syndrome and - given lack of certainty about an aetiological agent – appears to be similarly intractable to a variety of proposed therapeutic measures (Nickel, et al., 2008; Engeler, et al., 2017). The most current debate focuses on whether chronic prostatic inflammation is involved at all – or whether chronic muscular contractions in the pelvic region are the primary feature (Cohen, Gonzalez, & Goldstein, 2016).

Aetiological uncertainty, as well as limited effective therapeutic options, can have significant mental health sequelae as a result. There have been a considerable number of studies emerging which reveal a relationship between pain severity and depression in men with CP/CPSP (Krsmanovic, et al., 2014; Tripp, Nickel, Landis, Wang & Knauss, 2004; Clemens, Brown, Kozloff & Calhoun, 2006; Nickel et al., 2008). It has also been found that CP/CPSP can have a significant negative impact on the 'Quality of Life' of patients; comparable to myocardial infarction, angina, Crohn's disease, and diabetes mellitus (Wenninger, Heiman, Rothman, Berghuis, & Berger, 1996).

Regarding mental health corollaries, many men report feelings of depression, decreased social functioning and increased anxiety (Collins, 2003). Kwon and Chang (2013) have reviewed the literature linking depression with CP/CPPS, suggesting that depression can increase the severity of pain perceived by CP/CPPS sufferers. This point is further developed with reference to Tripp et al (in Kwon & Chang, 2013), who found that depressive symptoms can act as predictors of pain severity. It is concluded that depression may have a “profound long-term influence on the shaping of pain responses and pain outcomes [in CP/CPPS]” (Kwon & Chang, 2013, p.55; Harvard Medical School, 2014; Vasan, 2012). Krsmanovic, et al., (2014) also argue that ‘catastrophizing’ or ‘expecting the worst’ impacts significantly on quality of life in men with CP/CPPS too, and managing anxiety can help significantly.

Nickel and Shoskes (2010) explore the feasibility of a multimodal therapeutic approach to treatment of CP/CPPS. In their review, they report promising results from a treatment approach which assesses each patient on an individual basis and tailors treatment accordingly - the ‘UPOINT’ strategy – on the basis of identifying more specific clinical phenotypes amongst heterogeneous presentations, to allow more specific targeting of tailored treatments: (UPOINT – Urinary, Psychosocial, Organ Specific, Infection, Neurologic/Systemic, Tenderness of Skeletal Muscles). This model is still in its infancy however, and awaits ongoing studies to evaluate its construct and premises (Engeler et al., 2017).

Minimal research has directly addressed the experiential impact of having this illness. Chronic prostatitis often involves an additional sexual dysfunction component beyond chronic pain, potentially exacerbating any concomitant relationship difficulties (Ginting, Tripp & Nickel, 2011). Furthermore, there may be accompanying (and potentially embarrassing) urinary symptoms, such as frequency and incontinence, which may fuel further sleep difficulties. These symptoms are loaded with potential masculine signifiers, raising the issue of how men manage chronic illness (Charmaz, 1994; 1995). The issue of ‘performed

masculinities,' and the availability of alternative ways of 'being a man' are thus of direct relevance, as to how men experience illness – and associated disability (Gough & Robertson, 2010; Smith, 2013).

However, to date there has been one qualitative study of note into CP/CPPS – an Interpretative Phenomenological Analysis (IPA) of the experiences of chronic prostatitis sufferers (Jonsson & Hedellin, 2008). The five prominent experiential themes identified under the banner 'living with a troublesome disease' were: (1) Need for repeated confirmation – disease not life threatening nor leading inexorably towards cancer (2) Disturbed sleep and fatigue; (3) Concealing pain and problems – 'normalising'; (4) Enduring pain by performing activities and (5) Abrupt mood swings and limited sociality. However, this account covers current experiences and not meaning-making nor coping strategies over time.

The approach best suited to capture these critical features - which has importance for the development of coping 'stories' for clinician and sufferer alike - is a narrative one. This project thus aimed to pursue a narrative understanding of 'survivors' of chronic prostatitis – i.e. people who are currently experiencing or have experienced significant symptomatology, looking at strategies they have employed to optimally manage their illness over time.

Methodology

Frank (1997) has referred to illness as 'a call for narratives'. Furthermore, Kleinman (1988) and the later work of Charon (2005) have focussed on illness as narratives to be understood, rather than diseases to be diagnosed (King, 2014). Bury (1982) has highlighted how severe and enduring illness acts as a 'biographical disruption' in the life story - that is met with attempts to both understand and draw meaning from the illness experience (Bury, 2001).

Narrative methodologies are useful ways to capture the stories of illness experiences over time (Sools, Murray & Westerhof, 2015).

Finally, given this is a ‘masculine’ disease¹, ostensibly involving a male organ (the prostate), the issue of masculine performative expression - such as those identified by Riessman (2003) - will be explored, as well as the ‘positional level’ of the principal author (Murray, 2000).

Focus will thus also extend to the way the narratives are told, in addition to what is told, as well as the relationship of the principal researcher to the interviewees and data.

The focus of this current study was on asking men about their experiences of CP/CPPS over time and also trying to identify ‘positive ways’ of managing or ‘coming to terms’ with the illness. An inclusion criterion was for men who were at least a year post-diagnosis, to allow some degree of ‘adjustment’ to the illness. I hoped to uncover ways of coping that may be helpful not only to others with the illness, but for those involved in managing or responding to the illness process as well, e.g. doctors and support networks.

A semi-structured interview was thus developed with feedback from men from the British Prostatitis Support Association (BPSA) website forum, around ‘questions of relevance’ to assist understanding of the illness and its impact (Appendix 1: Interview Schedule.) This was consistent with the National Institute for Health Research call for research to be ‘service user’ led, along with the development of various resources to facilitate this (Armes, Barrett, Hindle, Lemonsky & Trite, 2011; Read & Maslin-Prothero, 2011).

Seven face to face interviews - two using Skype technology to include participants from difficult to access geographical locations (Hanna, 2012; Iacono, Symonds & Brown, 2016) - were conducted, including an ‘expert’ interview with a man who has both recovered from this

¹ Although female variations on CPPS are also significant, fuelled by gender specific contributory factors such as endometriosis etc. (Brawn, Morotti, Zondervan, Becker & Vincent, 2014).

illness and written a book about it – the novelist Tim Parks (2011). Iacono et al., (2016) argue that Skype interviews are suitable pragmatic substitutes for face-to-face interviews, with relatively comparable material generated - although this research is still in its infancy, and the authors recommend Skype be used to supplement (not replace) face to face interviews at this stage. Six of the interviews were conducted by the principal author (Nicholas Wood) and one face-to-face interview was conducted by the third author (Fahim Mughal).

Five further written narrative accounts were solicited from the participant pool within the BPSA online forum - in order to obtain narratives from men who may also have been keen to share their stories, but were perhaps intimidated by interviews. This format was also considered perhaps less potentially threatening for prospective participants than being interviewed by a woman researcher around a male condition that impacts on sexual functioning (Annum Quereshi, second author) – see, for example, Dwyer and Buckle (2009) on ‘insider-outsider’ perspectives in qualitative research² Both the interview and the written narrative studies were covered by the University of Hertfordshire’s Research Ethics permissions – PSY/11/11/NW and LMS/PG/UH/00048 respectively. Compliance for written narratives with the British Psychological Society (2013) guidance was also ensured, including debriefing and referral sign-posting if distressed.

Research Participants:

<<Insert Figure 1 Here>>

Participants and Recruitment:

² Appendix 2: This guide was an adaptation of Long and Bennett’s (2009) online narrative exploration of coping with Meniere’s Disease.

Participants were recruited through two main online discussion forums: The British Prostatitis Support Association (BPSA) and Prostate Cancer UK. Participants in the interview (X age = 46.5) and writing groups (X age = 49) were not too dissimilar age-wise, with both having a wide age-range (34-42 years). However, the writing group had a mean age of over 7 years longer experience with CP/CPPS (9: 16.6 years).

On My (Principal Author's) 'Positional Level' (Murray, 2000)

As part of my own positioning in relation to this research, I want to state here that I am in my sixth year of ongoing and active CP/CPPS symptomatology at time of writing and initially set out to try and obtain stories from others without sharing my own illness position, for fear of 'muddying the water' when it came to the elicitation of narratives. A further potential drawback considered in telling people you share a health condition is that they may assume certain level of shared narrative around the illness and thus deliver somewhat truncated accounts, with the implicit belief the researcher will somehow 'fill in the (shared) gaps' between them (Dwyer & Buckle, 2009). For this reason - and a wish not to foreground my own story - I initially held my own illness status in abeyance during the first few interviews. However, by the 3rd interview, it had become apparent that accounts were somewhat terse and perhaps restricted, the initial interview for example lasting only half an hour. On switching off the tape recorder at the end of the third interview, in some frustration at what felt like relatively limited material, I decided to divulge my own illness status. This appeared to fuel a rich and collaborative conversation for a further hour, which felt far more open and collegial in style, although the detail was to some extent lost, with the recorder off.

Interviews 4 to 7 - excluding P5, conducted by FM - were then additionally prefaced by my own illness status - given I had ongoing CP/CPPS for 4 to 5 years at the point of interviews and with a patient population used to being treated with some reservations and scepticism that

was apparent in for a discussions over the months to several years I had been a member, it eventually felt more than appropriate to share my illness status. Initially I felt it was important not to focus too much on my own experiences, so I decided I would try and hold these in abeyance as much as possible until the interview was over. However, following specific questioning responses from participant 4 after my own initial illness declaration, it became apparent to me it would be more productive to fully embrace emerging narratives as indeed shared and ‘co-constructed’.

With regards to the written narratives, these followed a somewhat similar scaffold of questions, looking at participants’ experiences over time around the impact of diagnosis, treatment and managing their illness (Appendix 2).

Analytic Process and Rigour:

The narrative thematic analysis followed implicit guidelines by Riessman (2002) and Squire (2013) around the delineation of narrative themes within storied accounts, e.g. focusing on ‘ordering and sequences’ (Riessman, 2002: 698) - as opposed to conducting cross-sectional thematic analyses (Braun and Clarke, 2006), perhaps incidentally occurring within narratives.

Findings from the interview and written studies were derived via a process of reading and rereading - in conjunction with audiotaped performance - to allow for performative analysis, as well as deriving coherent narrative content. Themes were developed via grouping stories within common contexts, to facilitate tracing a plotline of events, e.g. within the medical system (T1); experiences of CP/CPPS (T2) and ongoing attempts to manage this (T3).

These themes were compared and contrasted between authors, searching for triangulation, with final themes being developed and consolidated, via (1) expert and (2) participant consultation and agreement:

1. Independently sharing themes with both a narrative methodology expert, as well as an expert in CP/CPPS, to enhance credibility via expert scrutiny and agreement.
2. Taking themes back to the British Prostatitis Support Association (BPSA) online forum, checking for member validation. Feedback from online members were that themes: ‘accurately reflects the frustration and distrust some patients have with practitioners’ (T1); ‘really captures how this illness frustratingly comes and goes’ (T2); and ‘it shows how important it is for us that we keep trying to find ways to manage our illness better’ (T3).

One participant did ask for further direct research into the impact of CP/CPPS on men’s sexuality, including details on their sexual orientation (see Recommendations [3]).

This focus on the content of stories is necessitated by the shortage of published accounts around the illness stories of men with CP/CPPS. However, the findings are additionally framed by Murray’s (2000) ‘levels of analysis’ – although focusing primarily on the ‘personal’ level, the interpersonal context of men’s experiences with CP/CPPS is also explored.

Findings³: Summary:

Three major narrative themes emerged, but for the purposes of this paper, the primary focus will be on the first two themes. An overview of the third themes is provided below, to enable readers’ full data contextualisation, and is also published in Wood, Annum and Mughal (2017). All men (bar P2) had stories about lack of medical understanding and support (T1) and, given the difficulties managing erratic symptoms without medical guidance (T2), the issue of how to garner support and develop self-efficacy with CP/CPPS (T3) becomes

³ **Reporting protocol:** 1 Quotes are used with P = participant number. P1-P7 = interviewed men; P8-P12 = written accounts. Interviews refer page & line numbers; written accounts refer specific line numbers.

especially crucial. This is particularly the case for men, many who have difficulty sharing their pain and emotion (Performative analysis).

Narrative Themes: Personal Level:

1. Medical Stories: Blame and shame: ‘Medical’ stories featured prominently, throughout both the interview and the written narratives. These stories were mainly preoccupied with a felt lack of supportive response from the medical professions, especially urological consultants. Participants generally experienced the medical field as dismissing of their condition, making for a perplexing and fraught diagnostic process initially and moving on to an unsatisfying treatment experience. For those interested in a personal account of this theme, refer to Wood (2015).

2. The erratic nature of CP/CPPS: Debilitating, elusive, and fluctuating: The impact of CP/CPPS on functioning over time is described as one that both cripples the ability to function, but given it is also variable in the severity of its expression, it makes it hard to identify potential triggers or ways to grasp and manage the illness process in a way that feels as if there is some degree of inner control. The story of the illness is thus one which is hard to map out clearly and with any degree of certainty. Finally, even among one participant for whom there has been a good period of respite from the illness, there remains the fear it will return, such that the notion of ‘cured’ feels a tenuous and uncertain position – and one that is somehow mysteriously arrived at.

3. Ongoing struggles for coping and cures: Obstacles and Aids: The third narrative strand was around barriers to coping with the illness, including a variety of factors such as being overwhelmed, feeling unable to talk about it because of ‘being a man’, and the constant search for an as yet hidden but perhaps quick and miraculous cure. Strategies that seemed to help were ‘*making a stand*’ and *continuing to be active*, utilising *support* and keeping some

degree of *positive thinking* about the future. Finally, the search to uncover a '*meaning*' for the illness was paramount to providing a sense and purpose for suffering.

All participants spoke about the difficulty of coping with an illness that was poorly understood and without effective treatment approaches or clear prognoses. However, feeling defeated and the sense that their life had been 'taken over' by the illness was seen as being unhelpful to managing it, although sometimes hard to avoid. Participant 6 referred to the need to try and move away from the thought: '*I can't find a way round it*' to look for things that may provide some relative amelioration of symptoms, which for him were:

"...meditation, tai chi, hot baths, swimming... just keep going, keep my life going, so it doesn't interfere too much." (P6, p.2, ll.29-31)

Several men spoke about needing to adapt sitting arrangements and to physically keep moving as '*too much sitting*' had for them exacerbated their symptoms (Participants 1, 4, 5, 6 and 10).

Also of difficulty was shame and perceived restrictions on talking about their illness. Thus, Participant 7 spoke about how hard it was to talk about pain and discomfort when:

"...there aren't any visual symptoms of it you know" (P7, p.9, ll.23-24).

Participant 4 spoke about the fear of people 'backing off' if you chose to speak about the illness - and how hard it is to talk about, as a man:

"There's nothing shameful about it, but...any condition that involves the genital area and sexual equipment and such and kind of in a certain way threatens your male identity if you want ...generates a huge anxiety about it...and who wants to go into work and say yes, I've got this prostate problem. I need to pee every ten minutes. I've got a pain in my dick, it's not much fun is it?" (P4, p. 12; ll.6-10 and p.14, ll.20-21)

Many men also spoke about constantly searching for a cure, exploring dietary and alternative medicinal approaches, as well as ‘trigger point’ massage, meditation etc. The search for a cure for some included (in desperation) what they acknowledged may be to some extent ‘irrational’ items:

“...Magnetic therapy which involved me buying a massive high gauss magnet to sit on. This was at a time that a relative was getting good results with magnets for arthritis otherwise I might not have been so mad as to part with £90 for this thing”
[P9. 44-68].

Participant 1 admitted he had:

“...spent an arm and a leg on buying tablets and things but they’ve done nothing, you know.” (P1, p.15, ll. 21-22.)

Participants 5 and 7 both referred to making lists of potentially helpful items, even possible cures:

“I would kind of delay doing them, or one by one slowly, because it’s worse to have you know nothing to hope for, no like way of being able to sort of get over it...” (P7, p.10, ll.28-32).

In essence they both appeared to be very slowly working their way down the ‘list’, with some anxiety about not getting to the end too quickly, for fear that nothing would have helped, leaving them with deflated hope and little to look forward to.

Coping counterpoints to these difficulties included refusing to be overwhelmed by their illness, by ‘getting on with it’ (P1, p.10, l.25); ‘taking my mind off it’ (P2, p.14, l.12) and the importance of persevering with continuing one’s life and search for ways of managing the illness better. As P 9 stated (he eventually found the herbal supplement ‘Quercetin’ of help):

“...at least I can maybe offer encouragement to others by showing that there can be light at the end of the tunnel if you persevere and don't give up hope... Do be patient though, because I reckon my prostatitis raged for some 8 years before beginning to improve. Hope this proves helpful.” [P9. 112-114, 119-122]

Others spoke about the importance of sharing their illness stories with someone who cares. For several participants this has been family and partners (P1, 4, 6 and 7) - and for P2 this was his understanding and compassionate GP. As P4 also reported:

“...well I realised you could talk quite openly about to the children, without obviously you know being a whiner, but you say like I've got this big problem...” (P4, p.12, ll.12-14.)

Many men did not like to be seen as ‘a whiner’ – finding other forms of support helpful (particularly in the written narratives) – such as internet sites and patient forums (P. 9, 10, 12 and 13):

“At that point I had started looking on the Internet for Information. Why I didn't do this before? I don't know. I thought that the problem will just clear up on its own. Now I regret I didn't start looking for information before.” [P10. 44-46]

Several men reported on how beneficial it was to have an online support site to share their stories:

“I expressed my concerns on a prostatitis sufferers' forum, and, by chance, entered into communication with a urologist from Eastern Europe, who was keen to help.” [P12. 30-31]

Participants 1 and 4 did also offer cautionary caveats about the use of the internet though:

“...if you look too much on the internet it sort of scares you, if you find too much...and it all leads onto this...blimey, what have I got you know, but you must just, you know, look on the forum to you know talk to people...” (P1. p.14, ll.15-19).

The *search for meaning* was a means to finding ways to positively manage their illness.

However, there were variable experiences with this - for some, this felt a fruitless struggle.

As Participant 3 told me: *“I don’t make any sense of it. That’s the problem” (P3, p.7, l. 41.)*

Participant 5 said however: *“If you’ve got some understanding of how your mental state affects your physical state...that is an enormously helpful thing” (P3, p.11, ll. 7-11).*

Participant 4 tentatively wondered: *“Maybe it was about getting back into some kind of relationship with my body” (P4, p.20, l.16).* He went on to report that there appeared to be roughly three ‘phases’ to the illness that he could see:

“First phase is putting aside idea you have terminal illness...The next step you’ve got in front of you is have I got a life of serious chronic pain...that’s quite an anguished request. When I began to get out of that (healing) by the Grace of God, or whatever...’ (P4, p.21, ll. 22-27).

The Interpersonal Context of Interviews: Masculine Performances and Positioning:

The main differences between the written texts of participants 8 through 12 and Interviews 1 to 7 was obviously the differing interpersonal context involved in the interviews, from which ‘performative’ elements (see Methodology above) may perhaps be easier to infer. Murray (2000:340) refers to the ‘interpersonal level’ as the level where the narrative is viewed as “the result of a joint enterprise in which the two participants are both involved.” As an interesting exemplar of the interpersonal context of the interviews, I wish to highlight my first interview participant, who specifically requested for the interview to take place in his local pub. At one

point in the interview (which included discussions on sexual matters while drinking ale) he requested I turn off the recording until a neighbour who was also in the pub had passed.

I also noticed that while he drank his beer and spoke, his comments were generally restrained and terse, despite including an admissions of “*falling to my knees, crying my eyes out*” (P1, p.2, l.5) in the face of his illness. At several points he ‘matter of fact’ requested – ‘*next question*’ – as if it were an interrogation. To me, it appeared as if he needed to story his experiences within a context in which his masculinity would not be questioned. It also became apparent after the third interview, that accounts tended to be on the guarded side, as if men were both afraid to tell these stories of felt broken masculinity - and were also not used to being ‘heard’ or fully understood.

For this reason, from interview 4 onwards, I shifted my ‘position’, to indicate I was an NHS patient with ongoing CP/CPPS too. It was noticeable after changing my stance that responses were less guarded, perhaps also both shaped and encouraged by my own disclosures. So it was that the interactional dynamics shifted within the interview context, as did my relationship to the stories and the men themselves. By the end of the interviews, I became aware of how much I shared and appreciated the difficult stories that had emerged from men who – towards the end – had indeed felt more like ‘brothers’ than interviewees (Dwyer & Buckle, 2009).

Discussion:

1. Validity Issues:

There was significant overlap between the narratives elicited by written and interview methods. However, narrative performances appeared more clearly evident within the interview context and were also shaped by the changing ‘position’ (Murray, 2000) of the interviewer. Stories obtained when the interviewer was clearly identified as an ‘insider’ to the

illness experience appeared to be emotionally richer and less guarded. The possible drawback of this position is the need to try and ensure a "...close awareness of one's own personal biases and perspectives" (Dwyer and Buckle, 2009, p.59). For this reason, it was important to check developed themes with both experts in the field, as well as conducting a 'testimonial validity check,' to ensure the principal author's personal proximity to the subject did not 'spill out' too much into the data (Barker, Pistrang & Elliott, 2002, p.90) Kertstetter suggests most researchers are variously in the spaces 'in-between insider and outsider' - and this was the case for our small research team.

Another, perhaps preferable way of extending future research, would be to undertake a reflective interview, *in advance of* data collection, and to be transparent about the assumptions and personal position of interviewers *prior* to data collection (Etherington, 2004).

Toye, et al., (2013) have conducted a Meta-Ethnographic Analysis of Chronic Muscle-Skeletal Pain and their four strand thematic structure has some overlap to CP/CPSS stories as well. Their initial theme of "Patients struggling with the fundamental relationship with their body, and a sense that it is no longer 'the real me' partially maps onto trying to cope and make sense of CP/CPSS. Their second theme of 'A loss of certainty for the future, and being constantly aware of the restrictions of their body' also maps onto the debilitating and elusive impact of CP/CPSS. 'Feeling lost in the health care system and feeling as though there is no answer to their pain' echoes the medical stories of CP/CPSS patients. Finally. 'Finding it impossible to 'prove' their pain' is also part of the CP/CPSS experience, where diagnosis is by exclusion and many of the symptoms, such as pain - as reported above - are 'invisible'. It is apparent that other chronic illnesses of uncertain aetiology and prognosis may perhaps also share some of the narrative strategies of men with CP/CPSS.

2. Male Struggle and Survivor Stories:

What became apparent throughout all stories was the struggle to navigate an illness which has no clear aetiology, nor signposts or prognosis. This is particularly within a medico-social context where these stories have neither been given space nor validity and implicit shame is attached; i.e. the ‘moral’ components of illness narratives (Bury, 2001). The shame within these stories also acts to inhibit the expression of emotion and vulnerability, given this is a ‘masculine’ illness – indeed, an illness in which sexual performance may also be affected, but was often not talked about, even when explicitly asked for.

As Charmaz (2002) has argued, illness accounts are often incomplete and partial and not easy to tell, particularly within masculine constraints (Charmaz, 1994; 1995). The (gendered) context for these stories to be heard has hitherto been largely missing – and, when present within specific medical relationships, has often been discounted or experienced as trivialised. Riessman (2003) referred to the creation of “a lone hero on the move” (p.10) and “establishing himself as the powerful protagonist” (p.15), in male responses to diagnoses of multiple sclerosis – but perhaps these ‘performances’ were also partly in response to a woman interviewer?

The CP/CPPS stories, although including notions of ‘making a stand’ that perhaps portray ‘masculine’ stances, have also revealed however, performative moments of powerlessness and vulnerability, whereby a man can “collapse and cry like a baby”. These more vulnerable stories remain largely hidden and closeted though, perhaps only proliferating in closed internet forums where disclosures are perhaps less threatening, given the relative anonymity of the internet. (Several fragile stories were also shared in the anonymised written accounts.)

These ‘masculine counter-narratives,’ which challenge traditional accounts of masculinity in the West, appear to be increasingly prevalent, especially amongst younger men, as noted by research into men and sport in particular (Gough & Robertson, 2010; Smith, 2013; Smith, Bundon & Best, 2016). It appears that ‘orthodox’ or hegemonic’ masculinity, as displayed by ‘dominance, active, independence and the minimising of distress/emotion’ characteristics (Charmaz, 1994, p.270), are increasingly being challenged by ‘multiple’, ‘hybrid,’ and ‘inclusive’ models of masculinity, which are increasingly relaxing the constriction of rigid masculine stereotypes, as well as providing alternative models of development (Anderson, 2009; Bridges and Pascoe, 2014).

The importance of a supportive social context was particularly highlighted as crucial to aid coping with this difficult, elusive and intransigent illness. The online ‘male only’ forum has proven to be helpful for men in partnerships where ‘infertility’ is an issue (Hanna & Gough, 2016). Men benefiting from receiving ‘insider’ guidance and collegial support from other men struggling with these issues was highlighted. However, the tension implied by some men posting, who were worried they may be perceived as too ‘emoting’, suggests traditional masculine gendered constraints are still being tested.

Men have also spoken of their struggle to make sense of their illness, suggestive of Frank’s (1997) ‘chaos’ narratives - perhaps not unsurprising, given for most participants, their illness endures, without clarity or closure. However, many of the men have also attempted to make sense of their illness, despite uncertainty, indicating they are finding some meaning in the midst of chaos, akin to Frank’s (1997) ‘quest’ narrative, e.g. ‘*getting back into some kind of relationship with my body*’ (P4). This underlines the importance of *hope* in narratives, as P9 stated: ‘*there’s light at the end of the tunnel, if you persevere and don’t give up hope*’ (Smith and Sparkes, 2005). Seemingly central to this is an indication that illness is a psycho-social process as well, and requires acknowledging grief around loss of health, acceptance of illness

and pain (without abandoning the search for health) and a new way of relating to the ill male body and society (Charmaz, 1994; Charmaz, 1995; Frank, 1997; Owen, 2013).

Recommendations:

Recommendations include: (1) educating medical doctors of the importance of the ‘illness story’, rather than the disease per se (Kleinman, 1988; Wood, 2015), as well as supporting the move towards ‘narrative medicine’, which involves attempts to harmonise medical and experiential accounts (King, 2014). This is similar to the call to understand varied cultural beliefs and experiences around illness, rather than just imposing a Western diagnostic medical framework, which may be incompatible and jarring to recipients - and end up unwittingly decreasing their access and engagement with services (Nwoye, 2015). Narrative medicine is about understanding the illness story and the meaning of this for the patient, seeking to integrate this within a medical perspective (Charon, 2005).

(2) Given the difficulty around ‘understanding and controlling’ CP/CPPS, mindfulness approaches (and potentially acupuncture) in treatment may be particularly helpful (Qin, Wu, Zhou & Liu, 2016). Men have spoken of the need to keep hope and to persevere with their lives as much as possible, making adjustments as needed that are helpful, such as keeping active and avoiding prolonged sitting (Khoury et al., 2013). Furthermore, specifically tailored Cognitive Behaviour Therapy approaches may assist with the emotional difficulties, including depression and suicidal ideation, often concomitant with CP/CPPS (Nickel et al., 2008) and ‘acceptance’ approaches may also decrease the struggles with pain, illness and ‘catastrophizing’ (Krsmanovic et al., 2014; Owen, 2013). Given the paucity of qualitative and psychological research into CP/CPPS, further research is obviously strongly encouraged.

(3) The use of male online support forums for CP/CPPS appears to be potentially helpful (e.g. Hanna & Gough, 2016, on ‘male infertility’) and contesting conventional masculine gender

constraints and identifications may aid men in expressing the emotional burdens of their illness. Further detailed internet based research (e.g. supportive online forums) may be useful, to help uncover the variety of stories and ‘positions’ that men with CP/CPPS (and varying sexual orientations) may both tell and adopt. With regards to the internet, there also needs to be more research done into suitable sites for both support and reliable evidence, given poor quality sites can exacerbate problematic ‘catastrophising’ around this illness (Showghi & Williams, 2012).

(4) In future research, it may be helpful to seek out more extensive accounts from men who do indeed consider themselves to be ‘healed’, to further compare and contrast these findings.

(5) In the meantime however, we would argue that most crucially these stories need public space to be heard, given the fact that so little is known about this condition - and that what little is known, is mired in shame and stigma. There needs to be a dissemination of these stories into the public as well as the private sphere – these voices need to be both heard and ‘legitimised’. It is only by providing a context in which these stories are felt safer to share that sharing will indeed take place. We are only at the beginning of what needs to become a ‘community of stories’ about the masculine experiences of CP/CPPS – and how both medicine and society needs to shift to become a receptive ground for these stories, to validate private and often isolated suffering.

(6) For this to happen, perhaps a more ‘activist’ stance towards this ongoing research needs to be adopted (Murray & Poland, 2006), perhaps promoting positive media dissemination and developing policies. The wider ‘ideological’ level of the context for these stories thus also needs to be both researched and addressed (Murray, 2000).

References:

- Anderson, E. (2009). *Inclusive Masculinity*. Oxon: Routledge.
- Armes, D., Barrett, J., Hindle, D., Lemonsky, F. & Trite, J. (2011). *Mental health researchers' toolkit for involving service users in the research process*. London: MHRN
- Barker, C., Pistrang, N., & Elliott, R. (Eds.). (2002). *Research Methods in Clinical Psychology*. (2nd ed.). Chichester: John Wiley & Sons.
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2), 77-101.
- Brawn, J., Morotti, M., Zondervan, K.T., Becker, C.M. & Vincent, K. (2014). Central changes associated with chronic pelvic pain and endometriosis. *Human Reproductive Update*, 20(5), 737-747.
- Bridges, T., & Pascoe, C. (2014). "Hybrid" Masculinities. *Sociology Compass*, 8(3), 246-258.
- British Psychological Society. (2013). *Ethics guidelines for internet-mediated research*. Retrieved from <http://www.bps.org.uk/system/files/Public%20files/inf206-guidelines-for-internet-mediated-research.pdf>
- Bury, M. (1982). Chronic illness as biographical disruption. *Social Health and Illness*, 4(2), 167-182.
- Bury, M. (2001). Illness narratives: Fact or fiction? *Sociology of Health and Illness*, 23(3), 263-285.
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *The Sociological Quarterly*, 35(2), 269-288.

- Charmaz, K. (1995). The body, identity and self: Adjusting to impairment. *The Sociological Quarterly*, 36(4), 657-680/
- Charmaz, K. (2002). Stories and silences: Disclosures and self in chronic illness. *Qualitative Inquiry*, 83, 302-328.
- Charon, R. (2005). Narrative medicine: Attention, representation, affiliation. *Narrative*, 34(3), 261-270.
- Clemens, J.O., Brown, S.O., Kozloff, L. & Calhoun, E.A. (2006) Predictors of symptom severity in patients with chronic prostatitis and interstitial cystitis. *Journal of Urology*, 175(3), 963-966.
- Cohen, D., Gonzalez, J., & Goldstein, I. (2016). The role of pelvic floor muscles in male sexual dysfunction and pelvic pain. *Sexual Medicine Reviews*, 4, 53-62.
- Dimitrakov, J. D., Kaplan, S.T., Kroenke, K., Jackson, J. L., & Freeman, M.R. (2006). Management of chronic prostatitis/chronic pelvic pain syndrome: An evidence-based approach. *Urology*, 67, 881-888.
- Dwyer, S.C., & Buckle, J.L. (2009). The Space Between: On Being an Insider - Outsider in Qualitative Research. *International Journal of Qualitative Methods* (8), 54–63.
- Engeler, D., Baranowski, A.P., Borovicka, J., Cottrell, A.M., Dinis-Oliveira, P., Elneil, S., ... & Williams, C. (2017). Chronic Pelvic Pain Guidelines. *European Association of Urology*. Retrieved June 2nd 2017 from <http://uroweb.org/guideline/chronic-pelvic-pain/>
- Etherington, K. (2004). *Becoming a Reflexive Researcher: Using our selves in research*. London & Philadelphia: Jessica Kingsley Publications.
- Frank, A. (1997). *The wounded storyteller*. Chicago: University of Chicago Press.

- Ginting, J.V., Tripp, D.A., & Curtis Nickel, J. (2011). Self-reported spousal support modifies the negative impact of pain on disability in men with Chronic Prostatitis/Chronic Pelvic Pain Syndrome. *Urology*, 78, 1136–1141.
- Gough, B. & Robertson, S. (Eds.). (2010). *Men, masculinities and health: Critical perspectives*. Basingstoke: Palgrave MacMillan
- Hanna, E. & Gough, B. (2016). Emoting infertility online: A qualitative analysis of men's forum posts. *Journal of Health Psychology*, 20(4), 363-382.
- Hanna, P. (2012). Using internet technologies (such as Skype) as a research medium: A research note. *Qualitative Research*, 12(2), 239-242.
- Harvard Medical School. (2014). *2014 Annual report on prostate diseases*. Retrieved from <http://www.health.harvard.edu/mens-health/2017-annual-report-on-prostate-diseases> (Accessed June 4th 2017)
- Iacono, V., Symonds, P., & Brown, D.H.K. (2016). Skype as a Tool for Qualitative Research Interviews. *Sociological Research Online* 21(2), 12.
- Jonsson, K. & Hedelin, H. (2008). Chronic abacterial prostatitis: Living with a troublesome disease affecting many aspects of life. *Scandinavian Journal of Urology and Nephrology*, 42, 545-550.
- Kerstetter, K. (2012) Insider, Outsider, or somewhere in between: The impact of researchers' identities on the community-based research process. *Journal of Rural Social Sciences*, 27(2), 99–117
- Khoury, B., Lecomte, T., Fortin, G., Masse, M., Therien, P., Bouchard, V., ... Hofmann, S.G. (2013). Mindfulness-based therapy: a comprehensive meta-analysis. *Clinical Psychology Review*, 33(6), 763-71. doi: 10.1016/j.cpr.2013.05.005.

- King, H. (2014). The art of medicine: Narratives of healing: a new approach to the past? *The Lancet*, 383, 946-947. doi: [http://dx.doi.org/10.1016/S0140-6736\(14\)60471-2](http://dx.doi.org/10.1016/S0140-6736(14)60471-2)
- Kleinman, A. (1988). *The illness narratives*. New York: Basic Books.
- Krieger, J., Ross, S., & Riley, D. (2002). Chronic prostatitis: epidemiology and role of infection. *Urology*, 60(6), 8-12.
- Krsmanovic, A., Dean A. Tripp, D.A., J. Curtis Nickel., Shoskes, D.A., Pontari, P., Litwin, M.S., & McNaughton-Collins, M. (2014). Psychosocial mechanisms of the pain and quality of life relationship for chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS). *Canadian Urological Association Journal*, 8(11-12), 403-408.
- Long, A. F., & Bennett, T. (2009). Coping with Meniere's Disease: Experience and benefits from the use of complementary and alternative medicine. *Chronic Illness*, 5, 219-232.
- Magistro, G., Wagenlehner, F.M.E., Grabe, M., Weidner, W., Stief, C.G. & Nickel, J.C. (2016) Contemporary Management of Chronic Prostatitis/Chronic Pelvic Pain Syndrome, *European Urology*, 69, 286-297.
- Marszalek, M., Wehrberger, C., Temml, C., Ponholzer, A., Berger, I., & Madersbacher, S. (2008). Chronic Pelvic Pain and lower urinary tract symptoms in both sexes: Analysis of 2749 participants of an urban health screening project. *European Urology*, 55(2), 499-508.
- McNaughton Collins, M., Pontari, M.A., O'Leary, M.P., Calhoun, E.A., Santanna, J., Landis, J.R., ...Litwin, M.S. (2001). Quality of life is impaired in men with chronic prostatitis: the Chronic Prostatitis Collaborative Research Network. *J Gen Intern Med*, 16, 656-662

- Murray, M. (2000). Levels of narrative analysis in health psychology. *Journal of Health Psychology, 5*(3), 337-347.
- Murray, M. & Poland, B. (2006). Health psychology and social action. *Journal of Health Psychology, 11*(3), 379-384.
- Nickel, J. C., Berger, R., & Pontari, M. (2006). Changing paradigms for Chronic Pelvic Pain: A report from the Chronic Pelvic Pain/ Chronic Prostatitis scientific workshop. *Reviews in Urology, 8*(1), 28-35.
- Nickel, J. C., Mullins, C., & Tripp, D. A. (2008). Development of an evidence-based Cognitive Behavioural Treatment program for men with Chronic Prostatitis/Chronic Pelvic Pain Syndrome. *World Journal of Urology, 26*(2), 167-172.
- Nwoye, A. (2015). African psychology and the Africentric paradigm to clinical diagnosis and treatment. *South African Journal of Psychology, 45*(3), 305-317.
<http://dx.doi.org/10.1177/0081246315570960>
- Owen, R. (2013). *Living with the enemy: Coping with the stress of chronic illness using CBT, mindfulness and acceptance*. Oxon: Routledge.
- Riessman, C.K. (2002). Analysis of personal narratives. In Gubrium, J.F. & Holstein, J.A. (Eds.) *Handbook of Interview Research: Context and method* (pp. 695-710). London: Sage Publications.
- Riessman, C.K. (2003). Performing identities in illness narrative: masculinity and multiple sclerosis. *Qualitative Research, 3*(1), 5-33.
- Parks, T. (2011). *Teach us to sit still: A sceptic's search for health and healing*. London: Vintage Books.

- Qin, Z., Wu, J., Zhou, J. & Liu, Z. (2016) Systematic Review of Acupuncture for Chronic Prostatitis/Chronic Pelvic Pain Syndrome. *Medicine*, *95*(11): e3095.
doi: 10.1097/MD.0000000000003095
- Read, S., & Maslin-Prothero, S. (2011). The involvement of users and carers in health and social research: The realities of inclusion and engagement. *Qualitative Health Research*, *21*(5), 704–713.
- Showghi, N.N., & Williams, A.C. (2012). Information about male Chronic Pelvic and urogenital pain on the internet: An evaluation of internet resources. *Pain Medicine*, *13*(10), 1275-1283. doi: 10.1111/j.1526-4637.2012.01466.x
- Sools, A.M., Murray, M., & Westerhof, G.J. (2015). Special narrative health psychology issue. *Journal of Health Psychology*, *20*(3), 239-45. doi:10.1177/1359105314566616.
- Smith, B. & Sparkes, A.C. (2005). Men, sport, spinal injury and narratives of hope. *Social Science and Medicine*, *61*, 1095-1105
- Smith, B. (2013). Disability, sport and men's narratives of health. *Health Psychology*, *32*(1), 110-119.
- Smith, B., Bundon, A., & Best, M. (2016). Disability, sport and activist identities. *Psychology of Sport and Exercise*, *26*, 139-148.
- Squire, C. (2013). From experience-centred to socio-culturally oriented approaches to narrative. In Andrews, M., Squire, C., & Tamboukou, M (Eds.) *Doing Narrative Research* (2nd ed.,) London: Sage Publications.
- Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, Andrews, J. & Barker, K. (2013). A meta-ethnography of patients' experience of chronic non-malignant musculoskeletal pain. *Health Services and Delivery Research*, *1*(12). doi:10.3310/hsdr01120

- Tripp, D.A., Nickel Curtis, J., Landis, J.R., Wang, Z.P., & Knauss, J.S. (2004) Predictors of quality of life and pain in chronic prostatitis/chronic pelvic pain syndrome: findings from the National Institutes of Health Chronic Prostatitis Cohort Study. *British Journal Urology International*, 94(9), 1279-1282.
- UPOINT, (n.d.). Retrived March 31st, 2017, from <http://www.upointmd.com/>
- Vasan, S. (2012). Complications of Chronic Prostatitis. *Current Bladder Dysfunction Reports*, 7, 141-149.
- Wenninger, K., Heiman, J.R., Rothman, I., Berghuis J.P., & Berger R.E. (1996). Sickness impact of chronic nonbacterial prostatitis and its correlates. *Journal of Urology*, 155, 965–968.
- Wood, N. (2015). How to talk to someone with an “untreatable” lifelong condition. *British Medical Journal*, 351. doi: <https://doi.org/10.1136/bmj.h5037>
- Wood, N., Qureshi, A., & Mughal, F. (2017) Positioning, telling, and performing a male illness: Chronic prostatitis/chronic pelvic pain syndrome. *British Journal of Health Psychology*, 22(4), 904-919 doi: 10.1111/bjhp.12261.

Appendix 1: Semi-Structured Interview for Men with CP/CPPS

1. When did you first notice you were had symptoms consistent with CP/CPPS? (What Happened?) (How long have you had this?)
2. Can you describe the course of your condition? (When was a diagnosis made?)
3. How have you managed to cope with the condition? (What helps you manage this?)
4. What is the worst part of this condition for you? Has it impacted on sex life? If yes, how?
5. What treatments have you had? (If any) (What has helped, what has not helped?)
6. What sense do you make of the condition? (If any) (Why do you think you've developed CP/CPPS?)
7. What would you like others to know about this condition?
8. How has your life changed since this condition? What are your fears for the future? (What are your hopes for the future?)

APPENDIX 2 – Written Narrative Cues

‘What is your story with Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)?’

Feel free to write the story of your experiences with CP/CPPS however you wish and as lengthy as you like. You may describe, elaborate or include any part of your experiences in whichever way you feel comfortable, and some pointers you may find useful have been listed below.

- *Your story of obtaining a diagnosis for CP/CPPS*
- *Your experiences of receiving treatment for CP/CPPS*
- *How have you managed following your illness experiences?*
- *What has been the impact of CP/CPPS on aspects your life?*

Thank You! Please Submit To....

