

Survivor narratives of men with Chronic Prostatitis / Chronic Pelvic Pain Syndrome (CP/ CPPS)

Nick Wood
University of Hertfordshire / UEL

Background to CP/CPPS

1. There is a clear identified shortage of research and resources for men suffering from chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS), with the leading British charity, Prostate Action, referring to it as ‘the forgotten prostate disease.’
2. Prostate Action has now become ‘Prostate Cancer’!
3. So what is CP/CPPS??

CP/ CPPS – What actually is it?

- ▶ Unsurprisingly, no one's really *quite* sure[^].
- ▶ The 'condition' is defined as urologic pain or discomfort in the pelvic region, associated with urinary symptoms* and/or sexual dysfunction** for at least 3 months (Krieger, Nyberg, & Nickel, 1999)
- ▶ Possibly a heterogeneous range of 'conditions', covering currently 'agreed' typologies as overleaf...

Chronic Prostatitis / CPPS: Typologies (NIH, USA)

- 1) Acute Prostatitis <3 months
- 2) Chronic bacterial prostatitis >3 months; infection identified
- 3) ***Chronic prostatitis/chronic pelvic pain syndrome – no identified infection (95%)***
- 4) Asymptomatic inflammatory prostatitis

Impact of CP/CPPS

- ▶ CP/CPPS has a high prevalence rate, a recent European study suggesting in the order of 2.7%+ of men may be sufferers (Marszalek et al., 2008)
- ▶ CP/CPPS patient's QoL comparable to Crohn's disease, angina, myocardial infarction or undergoing chronic haemodialysis (Wenninger et al., 1996)*.

Impact & My Position

- ▶ CP/CPPS – onset March 2009; ongoing.
- ▶ Extremely difficult diagnostic process – invasive, frightening and by *exclusion*
- ▶ With diagnosis comes the admission there is no treatment – ‘Antibiotics (indefinite), chew anti-inflammatory and wait for it to burn out, anywhere between 4 years to...’
shrug (never??)
- ▶ Alone...

...But not alone...

- ▶ *Online support groups – British Prostatitis Support Association (BPSA: 1761 members to date).
- ▶ Shared suffering...
- ▶ and sampling access!
- ▶ But is this a ‘skewed’ sample – those who get better seem to leave...?
- ▶ What other qualitative studies have been done into CP/CPPS?

Study – singular*!

- ▶ Jonsson & Hedelin (2008) –
“Chronic abacterial prostatitis:
Living with a troublesome disease
affecting many aspects of life.
- ▶ IPA (n=10), X age = 44; disease
range 2–30 years!
- ▶ 5 key themes identified IPA – PTO

Living with a troublesome disease

1. Need for repeated confirmation – disease not life threatening nor leading inexorably towards cancer.
2. Disturbed sleep and fatigue
3. Concealing pain & problems – ‘normalising’
4. Enduring pain by performing activities and changing body positions – try keep active!
5. Abrupt mood swings & limited sociality – shame and anger...*

Why narrative?

- ▶ Illness as a ‘call for narratives’(Frank, 1995).
- ▶ Ask men about their experiences of CP/CPPS over time (Bury, 2001 – ‘biographical disruptions’)
- ▶ Focus on men who have been at least a year post–diagnosis, i.e. who may be more familiar with managing the illness, i.e. ‘survivors’
- ▶ & Focus on what helps...

Questions and Concerns

- ▶ **Interview schedule devised with help of BPSA members**
- 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?
- 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?)

Preliminary Findings

- ▶ Where do 'I' fit? (To tell or not to tell?)*
- ▶ Emphasise co-constructed stories – already have the weight of my own story – share status, but hold own story at bay until done.
- ▶ **Initial Narrative thematic threads (Riessman, 2008)**
- ▶ **Initial structural impressions**
- ▶ **Masculine performances**

Participant Details (n=5; aim 15)

Participant Number	Age	Duration of Illness (Years)
1	30	6
2	24	5
3	60s	10
4	57	4
5	50s	27

Initial Narrative Thematic Threads

- ▶ ***1. Struggling to make sense of CP/CPPS.***
- ▶ “Don’t make any sense of it, that’s the problem.” (P3)
- ▶ “Well, medical science can’t pin it down. It’s difficult.” (P2)
- ▶ ***A → Inability to predict the illness.***
- ▶ *“It sort of tricks you, you’re winning – and then it’s back.” (P1)*
- ▶ *“You keep searching for patterns, but I can’t find one.” (P3)**
- ▶ *“It just goes on and on, nothing really cures it.” (P5)*

Narrative Threads 2

- ▶ *2. How to keep managing multiple difficulties?*
- ▶ *A -> Masculine problems: sex and work*
- ▶ “I had a very painful ejaculation, as if on fire...” (P3)
- ▶ “It threatens your male identity, huge anxiety...” (P4)
- ▶ “I’ve got to carry on, to work for family...” (P1)
- ▶ “Who wants to say at work, I have prostate problems, a pain in my dick and I need to wee?” (P5)
- ▶ “It’ll somehow stop me from working.” (P1)

Narrative Threads 2: ...multiple difficulties.

- ▶ ***B. -> Ongoing Stress and Anxiety***
- ▶ “...stress appears to be a contributory factor...” (P3)
- ▶ “anxiety can make inflammation & pain worse...” (P5)
- ▶ “...annual PSA* test I get stressed about that.” (P5)
- ▶ So...

...3. How to Live with some Quality?

- ▶ ***A -> Value of an Understanding Other.***
- ▶ “...turning point was having a doctor who listened...” (P2)
- ▶ “...just type on the forum and someone emails back..” (P1)
- ▶ “...not easy to talk about, over dinner with strangers for example, but I talk to friends...” (P5)
- ▶ “I think you’ve got to be in a relationship with an understanding partner.” (P2)

3. How to Live with some Quality?

- ▶ ***B* → *Keeping Hope***
- ▶ “...being positive and thinking of a future is good, not ways to die...” (P2)
- ▶ “...find a way to keep looking at positive things too” (P4)
- ▶ ***C* → *Trying to Find Acceptance***
- ▶ “I accept I have this pain.” (P4)
- ▶ “...it’s not about believing it will get better, it’s more about accepting it for what it is.” (P5)**
- ▶ “...I just get on with it, I have a mortgage...” (P1)
- ▶ *Degrees of resignation and acceptance?*

4. Mostly, just Keep Going...

- ▶ “...keep busy, I have less pain when weight training...” (P1)
- ▶ “...yoga exercises and camomile tea; doing something at least...” (P4)
- ▶ “...stop thinking I have this terrible problem destroying my life and okay so I’m not well, but nor are so many others...” (P2)
- ▶ “...keep interested in something or someone of value...” (P3)

Where to Next?

- ▶ Structural analysis – these stories have no end; loop around, repeat, seem stuck at times – ? Reflecting partial, fragmented knowledge.
- ▶ Frank’s ‘chaos’ rather than ‘quest’ narratives – most participants not at ‘end’ of illness?
- ▶ Performing masculinities (Riessman) – e.g. discussing sexual difficulties in a bar.
- ▶ Sexy Secrets...the need to ask explicitly and speak openly. (‘Moral’ narratives, Bury, 2001.)
- ▶ “Evaluative dimension between personal & social” (that shape illness stories). (p.274)

Issues of Tension for Discussion

- ▶ The Role of 'I' in stories.
- ▶ Are these themes 'narrative enough'?
- ▶ And with thanks to my 'brothers' who have spoken
- ▶ Anything else...?

References

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