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??
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–inflammatories 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*!

- IPA (n=10), X age = 44; disease range 2–30 years!
- 5 key themes identified IPA – PTO
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...*
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)

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Age</th>
<th>Duration of Illness (Years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>30</td>
<td>6</td>
</tr>
<tr>
<td>2</td>
<td>24</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>60s</td>
<td>10</td>
</tr>
<tr>
<td>4</td>
<td>57</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>50s</td>
<td>27</td>
</tr>
</tbody>
</table>
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 \rightarrow 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)
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