Chronic Neuropathic Pain after Spinal Cord Injury.

An Interpretative Phenomenological Analysis of the Biopsychosocial Experience.
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Background

• Neuropathic pain arises from nerve damage.
• Over 60% of those with a spinal cord injury (SCI) suffer with chronic neuropathic pain (Kennedy et al, 1997; Modirian et al, 2010; Ulrich et al, 2007).
• This pain is debilitating, persistent over time, and resistant to treatment (Modirian et al, 2010; Siddall et al, 2003; Warms et al, 2002).
• Pain reduces quality of life (Donnelly & Eng, 2005), and increases risk of depression and anxiety (Perry et al, 2009).
Current State of the Literature Base

- Accepted view of pain from biopsychosocial model.

- Majority of neuropathic pain in SCI research is quantitative.

- Lack of understanding of the lived experience.

- Is there an aspect that isn’t being studied and treated?
This Study

• **Aim**
  ▫ To understand the experience of chronic neuropathic pain after SCI from a patient perspective, using a qualitative methodology.

• **Design**
  ▫ Qualitative, single interview study

• **Analysis**
  ▫ Interpretative Phenomenological Analysis (IPA)
Method

• Participants
  ▫ 8 outpatient participants were included in the analysis
  ▫ All had diagnosed neuropathic pain as a result of SCI

• Interviews
  ▫ Semi-structured, open-ended questions
  ▫ Audio recorded
  ▫ At time, day and location most convenient for the participants.

• Ethics
  ▫ NHS REC Ref: 13/LO/0558
  ▫ R&D
  ▫ The University of Buckingham School of Science Ethics Committee
  ▫ National Spinal Injuries Centre
Results

- 3 Superordinate Themes:
  - The Chasm Between Biomedical Perspectives and Patient Beliefs and Needs
  - The Battle for Ultimate Agency of Life
  - The Coexistence of Social Cohesion and Social Alienation
## Presence of Each Superordinate Theme

**Master Table of Presence of Superordinate Themes for the Group**

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<th>James</th>
<th>Harry</th>
<th>Daniel</th>
<th>Rebecca</th>
<th>Dave</th>
<th>Emma</th>
<th>Sharon</th>
<th>Sean</th>
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N.B. Names changed to protect the patients’ identity
Superordinate Theme Breakdown

• The Chasm Between Biomedical and Patient Beliefs and Needs
  ▫ Excessive Reliance on Insufficient Medication
  ▫ Relationships with HCPs: Losing Faith
  ▫ Lack of Input into own Care

• The Battle for Ultimate Agency in Life
  ▫ Pain is Winning
  ▫ I am Winning

• The Coexistence of Social Cohesion and Social Alienation
  ▫ SCI Population are United but Alone in Experience
  ▫ Painful Self as an Affliction on Able-Bodied
The Chasm Between Biomedical and Patient Beliefs and Needs

• Excessive Reliance on Insufficient Medication
  ▫ ... all these kinds of drugs, but, I’ve tried them, and I’ve rejected them. Because it makes no difference whether I have them and I’m not prepared to take high doses constantly, and be a zombie, and I’d rather put up with a bit of pain than take those drugs and have a blank mind. Because that’s how they make you feel. It’s like your thoughts are trying to fight their way through a thick lump of fog.
  
  ▫ Harry: 6, 135-139
The Chasm Between Biomedical and Patient Beliefs and Needs

- Relationships with HCPs: Losing Faith
  - *Like I’ve said to my doctors ... it’s taken this long to get an appointment sorted out. As soon as I went to [local hospital] they were like couldn’t believe that I wasn’t with a pain team ... they said “your doctor should have done it”. But my doctor said to ring them, when I said “I haven’t got a number”, he looked at a bit of paper and said “well I haven’t got the number either”. So I was like, alright well that’s a load of good then.*
    - Daniel: 18, 427-432
The Chasm Between Biomedical and Patient Beliefs and Needs

• Lack of Input into own Care
  ▫ *I felt I went to my GP and I felt so frustrated that my whole life was being judged by someone else in order to say “no well we know better than you”. As much as it’s my [said with emphasis] experience, it’s my pain, I’m telling you my experience, you don’t seem to be listening because you’re not giving me what works for me.*
  ▫ Emma: 21, 492-496
The Battle for Ultimate Agency of Life

- Pain is Winning
  - ... you can’t get rid of it, you can’t escape it.
    James: 13, 323
  - ... the only way that I can describe it is that ... you’re doing whatever you’re doing ... and a little person inside flicks a switch and shuts you down. It just, literally just collapse.
    James: 14, 330-332
The Battle for Ultimate Agency in Life

• I am Winning
  ▫ *Either you give up and die, or you get on with it. So I get on with it ... and I bounce back again, I’m fine ... I’m not selfish or anything but, to do with the pain side I’m not going to let it get in the way of it. You know what I mean take over.*
  ▫ Rebecca: 10, 224-229
The Coexistence of Social Cohesion and Social Alienation

- SCI Population are United but Alone in Experience
  - *I think being around people in wheelchairs more might give me ... [unfinished sentence] I’m looking forward to that ... that’s why they call [specialised spinal unit] bubble world, because everyone’s the same, you don’t feel like an outcast, do you know what I mean?*
  - Daniel: 20, 480-482
The Coexistence of Social Cohesion and Social Alienation

• Painful Self as an Affliction on Able-Bodied
  ▫ ... my wife, she retreats into her shell when I’m in agony, she’s seen it so many times [...] and because it impacts on her so much, she could even ... enter a sort of phase of to get on with it you know. “For God’s sakes”, you know? Become irritable with me ...
  ▫ Harry: 14, 319-322
  ▫ ... it makes me feel as if my pain is responsible for her emotional pain ... it makes me feel uncomfortable ... because she loves me she doesn’t want me to be so distressed and knowing that I am distressed with all the pain and there’s nothing she can do.
  ▫ Harry: 14, 328-332
Discussion

- Confirms of biopsychosocial model in experience of SCI pain.
- Identifying discrepancies between support currently offered and the support that patients want/need:
  - HCPs should offer more than just medication.
  - Need to teach SCI patients how to regain control over their lives.
  - Support for pain education for able-bodied family and friends.
- Knowing which aspects of the pain experience influence an outpatient’s well-being.
- Enhanced outpatient support from healthcare professionals.
Next Steps

• Questions:
  ▫ Are these experiences specific to outpatients?
  ▫ How do inpatients experience neuropathic pain?

• Inpatient Phase (Ethics approved)
  ▫ Match current study for comparison
  ▫ Potential to map the ‘journey’ of pain from inpatient to outpatient.
  ▫ Does pain change from in- to outpatient?

• Room for future research:
  ▫ Why is medication ineffective?
  ▫ Interventions for teaching life control? Mindfulness?
  ▫ How does pain education for friends and family affect outcomes?
References


Thank you!