A QUALITATIVE STUDY EXPLORING DISTRESS IN PSORIATIC ARTHRITIS

Chisholm A¹,⁵, Pearce CJ¹,⁵, Roberts C², Chinoy H³,⁴, Warren RB¹,⁴, Bundy C¹,⁵.

¹Manchester Centre for Dermatology Research, ²Manchester Medical School, ³Centre for Musculoskeletal Research, ⁴Salford Royal NHS Foundation, ⁵Manchester Centre for Health Psychology. University of Manchester, Manchester Academic Health Science Centre, Manchester, UK.
Background

- High distress levels in inflammatory arthritis\(^1\)
- High distress levels in psoriasis\(^2,3\)

  (depression, anxiety, suicidal ideation, stigma) but often goes undetected in clinical practice\(^4\)

- 1.8 million people in the UK diagnosed with psoriasis - 30% of people with psoriasis develop PsA\(^5\)

\(^1\)Kotsis et al 2012; \(^2\)Kurd et al., 2010; \(^3\)Singhal et al., 2014; \(^4\)Richards et al., 2004; \(^5\)Gladman et al, 2005;
PsA characterised by joint inflammation, tender/swollen joints, stiffness (prolonged in mornings), and pain\(^6\)

Substantial physical, psychological and social impact upon patients’ lives\(^7\)

People with PsA are susceptible to distress related to psoriasis and arthritis but it is unknown how people experience living with PsA and what drives distress directly related to this condition

\(^6\)Yamamoto et al, 2011; \(^7\)Brodzsky et al, 2010
Research question: What drives distress in people living with PsA?
Method

Recruitment:
Patients diagnosed with PsA and who attended a combined dermatology-rheumatology clinic invited to take part in an in-depth, semi-structured, qualitative research interview.

Interviews conducted at patients’ homes, hospital, or via phone. Digitally audio-recorded and transcribed verbatim.

Interview guide structured around illness representations model\(^8\): i.e. beliefs about PsA cause, identity, timeline, control/cure, consequences, emotions, and illness coherence.

We explored patients’ feelings and thoughts about PsA, experiences of living with and self-management strategies for PsA.

\(^8\)Leventhal et al, 1984
Method

Participants:
- N=22
- Mean age = 44 years; range 27-60
- 12 males, 10 females
- Receiving treatment in specialist centre in Northwest UK

Thematic analysis and principles of framework analysis\(^8,^9\)
Two authors independently coded the dataset and emergent themes were defined through group discussions with the research team.

**Stage 1:** Leventhal et al.’s model used as initial coding framework to identify **key beliefs** about PsA

**Stage 2:** Patterns across the data were then organised into emergent themes

\(^8\text{Braun & Clarke, 2006}; ^9\text{Richie & Spencer, 1994}\)
Results
4 main themes

1. Consequences
2. The influence of other people
3. Put up and shut up
4. Why me?
1. Consequences  Patients felt frustrated and hopeless about how physically restricting PsA is. They feared their functioning would deteriorate progressively and that they would have to depend upon other people.

**ANTICIPATORY FEAR OF DETERIORATION**
I’m like, am I going to end up in one of those motorised scooters, you know...I don’t know if it’s a degenerative...nobody has ever said anything...I’m gonna end up in a wheelchair, it’s just my worry (ID15)

**FRUSTRATION**
When it’s stressing me out or, it makes me upset that I can’t do things, especially with my little boy...it makes me frustrated that I can’t do what I want to do (ID9)

**FEARING DEPENDANCE**
I’m thinking I’m going to be either a drain or strain, either on society and my family or on the service itself (ID1)

**HOPELESSNESS**
It was destroying me really, and I just got to a point where I just thought, I can’t go on with this (ID3)
2. The influence of other people.

Patients described varied degrees of social support, and often highlighted that people don’t always take their condition seriously.

**DISMISSED BY HEALTHCARE PROFESSIONALS**
I'd gone to see a GP and been dismissed and told, don't be silly, there's nothing wrong with you, even though I said, I've got psoriasis and there's a history of psoriasis and arthritis in my family. I had one GP say to me, I don't know what you're making a fuss about, and I was like, I can't use my hands in my morning. (ID12)

**FAMILY BLAME/JUDGEMENT**
I always found walking difficult and when I went to the chiropodist the first time on my own they told me I had deformed feet...My mother went mad. She swore it was me screwing my feet into shoes (ID11)

**ISOLATION**
I’m fast learning you have to look out for yourself, cause no one else looks out for you, you know (ID4)
3. Put up and shut up.

Patients described hiding their distress from those close around them, often to reduce negative affect, protect personal independence, and to fight their condition.

**BRAIN VS BODY**
Absolute agony, and my brain’s telling me, stop, stop, but I’m thinking, no, the weather’s good, get some washing out (ID11)

**AVIODANCE COPING**
Take as many painkillers as you can, try and get as much sleep as you can, because when you’re asleep you’re not in pain...when I’m bad, I wish I could sleep 24 hours a day. (ID13)

**MY RESPONSIBILITY: HIDING DISTRESS**
Oh, I’m very good at hiding things (ID4)

**IMPRESSION MANAGEMENT**
The polite British thing is to say, oh yeah I'm fine thanks. But actually I'm thinking, every bone in my body hurts and I'm so tired I want to cry. (ID12)
4. Why me?

Patients expressed a deep sense of injustice, described ways in which PsA threatened their identity and often made negative comparisons with other people.

**OLD BEYOND MY TIME**
It was like being trapped in an old woman’s body at the time, and I was 36, I should have been in the prime and I couldn’t even walk (ID10)

**SOCIAL COMPARISON**
You feel envious of people that are living the life that you should be living (ID10)

**INJUSTICE**
You just lay there and you’re thinking why me? What have I done? What have I done in my life? You know I’ve not done wrong, I’m not a bad lad, I’ve not killed anybody (ID13)

**SPOILED IDENTITY**
I don’t have any friends...I feel so disconnected with them, I don’t feel like I belong to them in the same group, or as young people (ID8)
Discussion

As in psoriasis and inflammatory arthritis we showed high levels of distress in patients living with PsA also.

Their distress relates to:

- *Fears about the consequences and timeline of the condition*
- *Reactions of people around them*
- *Coping style*
- *Feelings associated with a loss of personal identity*
Discussion

Salient emotions (e.g. fear / hopelessness), perceptions (e.g. I should cope with PsA alone) and misperceptions (e.g. my functioning will deteriorate exponentially)

These could be addressed by healthcare professionals in order to better identify and manage distress with these patients.

Further work:
- Systematically investigate levels of distress in individuals
- Recommendations for healthcare professionals regarding how to measure and manage distress with individuals
Thank you for listening – questions?

Email: Anna.Chisholm@manchester.ac.uk

Acknowledgements / PsA research team:
Christina Pearce
Chris Roberts
Hector Chinoy
Richard Warren
Chris Bundy

Thank you to all the patients who took the time to share their experiences with us.
References:


