**Title: Distress, misperceptions, poor coping and suicidal ideation in psoriatic arthritis: A Qualitative study**

**Short title: Exploring distress in psoriatic arthritis**

Anna Chisholm1,2, Christina J Pearce1,2, Hector Chinoy3, Richard B Warren1, Christine Bundy1,2

1 Manchester Centre for Dermatology Research, Manchester Centre for Health Psychology, University of Manchester, Manchester Academic Health Sciences Centre, Manchester, UK.

2 Manchester Centre for Health Psychology, University of Manchester, Manchester Academic Health Sciences Centre, Manchester, UK.

3 Manchester Centre for Musculoskeletal Research, University of Manchester, Manchester Academic Health Sciences Centre, Manchester, UK.

Corresponding author: Dr Anna Chisholm

Postal address: Manchester Centre for Dermatology Research, Institute of Inflammation and Repair, Stopford Building, University of Manchester, Oxford Road, Manchester, UK, M13 9PL.

Email: anna.chisholm@manchester.ac.uk

Phone: 0044 +161 2750710

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**ABSTRACT**

**Objectives**  Psoriatic arthritis (PsA) is associated with significant distress and can be life-ruining. Reducing distress can improve quality of life and disease outcomes. Quality of life measures broadly identify the extent to which PsA impacts on people’s lives but do not enable clinicians to address PsA specific distress in the clinic setting. This study identified the factors underlying PsA-related distress.

**Methods**  Semi-structured individual interviews were conducted in the UK with adults with PsA. Interview questions were theoretically informed by the Common-Sense - Self-Regulatory Model (CS-SRM). Two stages of data analysis, in line with Thematic and Framework Analysis principles involved coding pre-determined CS-SRM components and identifying any additional emergent themes. Constant comparison techniques allowed for patterns across CS-SRM components to emerge inductively from the data.

**Results**  24 people with PsA participated (54% Male; aged 27-71; years since onset ranged between 4 months and 29 years). Four core themes comprising clusters of illness beliefs, emotions and related behaviours emerged accounting for patient distress: 1) Restrictions, 2) Role of others, 3) Resentment, 4) Resignation. Suicidal ideation in the sample was commonly expressed and patients feared exponential degeneration of their condition. Patients reported the condition being dismissed or belittled by others and therefore hiding their distress from people around them.

**Conclusions**  People with PsA experience significant disease-related distress, including suicidal ideation. Misperceptions, ineffective coping styles (e.g. avoidance/blocking), and negative emotions should be actively identified and addressed with people with PsA.

**INTRODUCTION**
Psoriatic arthritis (PsA), a long-term inflammatory condition, can lead to joint damage and physical disability impacting greatly upon health related quality of life (HRQoL) [1]. PsA affects between 7% and 48% of people with psoriasis, often developing around a decade after psoriasis onset [2]. Individuals with PsA are therefore likely to be living with two potentially life-ruining long-term conditions, and consequently are susceptible to distress related to both skin *and* joint involvement. Difficulties diagnosing PsA can also cause identification and treatment delays, contributing further to poor disease outcomes and distress [3].

Psychological distress refers to the negative emotions (anger, sadness, worry, apathy, stress) individuals experience in relation to ill-health. This is demonstrated in PsA with people experiencing high levels of depression, anxiety and concerns about bodily symptoms [4]. Distress is known to contribute to health status in long-term conditions including other dermatological and rheumatic disorders [5]. Thus HRQoL and disease outcomes could be improved by addressing distress in PsA.

Little attention has been paid to understanding the potential *reasons* underlying this distress despite it being influenced by more than just disease severity. For example, distress can remain high when psoriasis-related disease severity is low [6]. Thus a linear relationship between distress and disease severity does not exist and other factors are implicated in disease-related distress.

Peoples' beliefs about their condition can influence their emotional and behavioural responses to it and psychological approaches addressing these cognitiove-behavioural factors indicate benefit for patients’ quality of life and disease activity [7]. The Common-Sense-Self-Regulatory Model (CS-SRM) outlines specific categories of illness beliefs that people commonly hold which predict health-related coping and behaviour [8]. These categories include beliefs about: what *caused* the condition, its *identity* (e.g. symptoms), *timeline* (e.g. duration/temporal nature), *consequences*, and the ability to *cure* or *control* the illness. Together these beliefs and associated emotional processes make up individuals’ illness representations, and are known to predict patient outcomes for a range of conditions including diabetes and cancer, with findings indicating effects upon patients’ mood, self-management, daily functioning and coping strategies. In psoriasis, illness representations predict frequency of outpatient clinic visits, pathological worry, physical and social functioning [9].

Research has not investigated illness representations in people with PsA or considered how they might relate to patients' ability to self-manage, or maintain physical/social functioning. The current study sought to explore those factors in patients with PsA.

**METHODS**

Ethics approval was granted by the University of Manchester Research Ethics Committee (ref.14223). Adults (>18 years old) diagnosed with PsA (≥3 swollen and ≥3 tender joints in line with current recommendations and CASPAR criteria) [1, 10] were invited to participate in an in-depth, semi-structured research interview. Patients were identified from a combined rheumatology-dermatology hospital clinic run by authors HC and RW. People with differing demographic contexts were purposively sampled to try to capture varied views and experiences of PsA [11]. Maximum variation was sought in terms of patient sex, age, disease duration, and severity (determined by treatment type due to lack of available information on other objective severity measures).

 Interviews were conducted by AC/CP within the hospital or patients’ homes Interview questions were informed by, the CS-SRM [8] which guided explorations of patients’ experiences of PsA. Examples of questions include ‘How much control do you have over the condition?’ (*control*), ‘How do you see it progressing over time?’ (*timeline*), and ‘What do you think caused your PsA onset/flares’ (*cause*). The topic guide was flexible to allow for unanticipated issues and ideas to emerge from patients regarding PsA-related distress (e.g. ‘Tell me about your experience of living with PsA’). All interviews were digitally audio-recorded and transcribed verbatim.

The qualitative analysis approach combined elements of Framework and Thematic Analysis [12,13] to identify distress-related factors. Framework analysis guided initial identification of beliefs underlying individual’s experiences of distress; thematic analysis facilitated the overarching indicative processes involved in combining these beliefs with other emerging elements (e.g. people’s emotions/behaviours) accounting for distress. Specifically, data were first coded according to the pre-determined CS-SRM components (i.e. beliefs about the cause, identity, timeline, consequences, perceptions of control/cure PsA, and related emotional responses). Data not fitting within these categories were noted as additional emergent ideas (e.g. healthcare provision experiences). Subsequently, an inductive identification of overarching themes and sub-ordinate categories was conducted to identify patterns across the dataset. Using constant comparison techniques, data collection and analysis occurred iteratively and in parallel [14]. Analysis ceased when no new data emerged from the dataset, and the analytical categories become firm in that themes and sub-ordinate categories were distinguishable and clearly definable rather than fluid.

**RESULTS**

Twenty-four patients completed interviews lasting between 26 and 79 minutes (Mean = 45.79, S.D. = 11.31 minutes); 13/24 were male (54.2%), 21 White British (87.5%) and three Asian (12.5%). Ages ranged between 27 and 71 years (Mean = 45.63; S.D. = 9.99 years). PsA duration ranged from 4 months to 29 years (Mean = 9.67, S.D. = 9.29 years). Supplementary files are available displaying patient-reported comorbidities and current treatments.

Four core themes accounted for PsA-related distress experienced by patients: 1) Restrictions, 2) Role of Others, 3) Resentment and 4) Resignation (see Table 1).

**[Table 1 placed here]**

**Theme 1: Restrictions**

Patients reported consequences of living with PsA that affected all areas of their social, work and family lives but most prominently described how physically restricting PsA was. Patients feared their condition would rapidly and unexpectedly deteriorate, resulting in dramatic loss of functioning. Patients’ beliefs that PsA severity would decline over time was contradicted by reports that their condition had remained relatively stable since its onset, with only treatment resulting in notable changes to severity. Concerns about losing personal independence were also reported, with some worrying about the burden this would place on others, or the emotional impact (e.g. embarrassment) that could be imposed.

In addition to fearing future consequences of PsA, patients described how it contributed to limiting their past/current life course and decisions. PsA had prevented romantic relationships, starting a family, engaging in school, developing desired careers, learning to drive, or moving house. The profound consequences and restrictions reported were often accompanied by feelings of helplessness and hopelessness. Patients said they were unable to visualise a future for themselves and often expressed suicidal ideation. For some patients this related to the impact of PsA upon their lives (e.g. damaged marriage/family life) and for others it was directly related to PsA symptoms (e.g. worsening/permanence of pain).

**Theme 2: Role of others**

Patients acknowledged instances in which significant others (i.e. family members/colleagues) offered physical and emotional support while in contrast feeling that people don’t take their condition seriously. They reported anger and low mood from being dismissed or disbelieved by members of the public, family or friends, and by health care staff.

Some positive experiences in healthcare settings were reported, particularly in relation to being referred to experts in PsA, and receiving life changing pharmacological treatments. However, some described early dismissal of symptoms in non-specialist settings, healthcare professionals being disinterested in the impact of PsA on their lives, their concerns not being taken seriously, and being made to feel like an inconvenience.

Patients felt the healthcare system had failed to prepare them for living with PsA and the influence it would have in their lives. Specifically, that existing patient resources were poor at explaining the physical and psychological factors associated with PsA. Patients expected more support from the healthcare system to manage life with PsA or to identify symptoms earlier to enable a more prompt diagnosis.

 **Theme 3: Resentment**

Throughout patients’ accounts of living with PsA, they expressed a sense of injustice, describing ways in which PsA threatened their personal identity and making negative comparisons to other people. They reported feeling it was unfair that they had to live with PsA, especially considering they hadn’t contributed negatively to society or engaged in any ‘punishable’ activities such as smoking, drinking, taking illicit drugs or even committing murder. They focused on personal characteristics that they believed had been damaged by living with PsA, including not being perceived as young, sexually attractive, strong, or a good parent.

Seeing other people who patients believed should be less able than them acted as a reminder of the abilities or characteristics they felt they lacked. They felt envious of other people living in a manner they felt they should be living.

**Theme 4: Resignation**

In managing day-to-day, patients described attempts to push through, hide or avoid aspects of their condition. In line with this, they frequently reported that they simply put up with the symptoms and consequences of PsA. Patients engaged in internal brain-versus-body conflicts about whether to be active or rest; these battles were resource-intensive causing fatigue and distress. Despite the fact that patients expressed feeling isolated and unsupported by others, they concealed their distress from others to preserve a positive frame of mind, maintain independence or protect others from unnecessary distress.

Instead of seeking support or engaging in active coping strategies, patients reported using avoidance and distraction to maintain everyday functioning and quality of life. Methods of escapism included alcohol consumption, pain killers, sleeping pills, socialising, comfort eating and immersing oneself in daily stressors (e.g. managing bills/ finances). Generally, patients either reported passive coping strategies or expressed that they felt unable to do anything to cope.

**DISCUSSION**

This is the first theoretically informed study demonstrating that people living with PsA experience significant disease-specific distress including suicidal thoughts. In line with the CS-SRM [16], our findings indicate that a range of PsA-related *thoughts* (e.g. my functioning will deteriorate exponentially), *emotions* (e.g. fear /frustration), and *behaviour* (e.g. avoidance / distraction coping) can characterise people’s experiences of living with PsA. Given that these factors are amenable to change, and that changes in illness beliefs can influence physiological outcomes including pain [15], these results identify modifiable factors which could improve patient wellbeing and quality of life. Thus in addition to assessing patient distress via established measures [16, 17], clinicians should also identify and address patient-specific beliefs, emotions and behaviours which may be driving their distress. This is particularly important given this study finding that suicidal ideation in this population may be actively hidden in everyday life and when seeking medical care. Further research is required however to identify the prevalence of suicide risk within this population.

Patients in this study held potentially unfounded fears about the extent to which their condition would deteriorate. This finding offers an opportunity for clinicians to influence distress levels in these patients by asking questions to assess patients’ understanding of the condition and challenging any unfounded beliefs. Although clinical guidelines state that immediate rheumatology referral is required upon identification of PsA symptoms [1], and research suggests that diagnostic delay in PsA has reduced between 2000 and 2014 [18], reports of primary care clinicians failing to recognise and refer appropriately was common. Overcoming barriers to implementing these referral guidelines should enable faster treatment provision and may reduce patient distress, specifically surrounding beliefs about the extent to which people will support them or take their condition seriously.

This study showed, in line with other stigmatising long-term conditions such as lung cancer, that people may conceal aspects of their illness in order to cope [19]. Passive coping and engagement in potentially harmful behaviour such as acohol use was reported by patients in this study; support in using alternative coping methods may be particualry important in this group who are at increased risk of cardiovascular disease risk [20].

Overall, these findings suggest more integrated/accessible psychological support is required for people with PsA. Patients’ illness beliefs should be actively identified and addressed within clinical consultations and the role of psychologists with specialist interests in rheumatology should be considered. Development/improvement of support materials may also help to prepare people to plan for and manage the impact of PsA across the life course.

**Key messages:**

* Patients with PsA can experience significant disease-related distress including suicidal ideation
* Misperceptions, insufficient support and poor coping strategies can drive PsA-related distress
* Patient-specific illness beliefs can underlie the factors associated with PsA-related distress

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**Conflict of interest statement**

The authors declare no conflicts of interest

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**Supplementary file 1.** Patient reported conditions other than PsA / psoriasis

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| **Patient ID number** | **Conditions other than PsA and psoriasis** |
| 4 | AA Amyloid; Renal failure; Uveitis; Panniculitis; Osteoporosis |
| 8 | Uveitis |
| 10 | B12 deficiency and Anaemia; Neurofibromatosis (NF1) |
| 11 | Ankylosing Spondylitis; Type 2 Diabetes; High blood pressure |
| 12 | High blood pressure; Asthma; Polycystic ovaries |
| 13 | Angina |
| 14 | Hyperthyroidism; Depression |
| 15 | High blood pressure |
| 17 | Raised Cholesterol |
| 19 | Type 1 Diabetes |
| 20 | Proximal Atrial Fibrillation |
| 21 | Diabetes; Thyroid problems; High blood pressure; High cholesterol |
| 22 | High blood pressure |
| 23 | Type 2 Diabetes |

**Supplementary file 2.** Reported treatments for PsA and/or psoriasis currently used by patients

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| --- | --- |
| **Treatments for PsA (and/or psoriasis)** |  **No. of patients**  |
| None *(due to transitioning between treatments / other health complications)* | 3 |
| Anti-inflammatory / pain-killers *(e.g. Naproxen, Co-codamol, Tramadol)* | 9 |
| Topicals/Emollients *(e.g. Coal Tar shampoo, moisturisers, steroid creams)* | 6 |
| Systemics *(e.g. Methotrexate, Ciclosporin, Leflunomide, Sulfasalazine, Acitretin)* | 13 |
| Light (PUVA) | 1 |
| Biologics *(e.g. Adalimumab, Ustekinumab, Secukinumab)* | 6 |

*Note. Patients could report using more than one treatment at the same time hence the total number being greater than the sample size (n=24).*

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| --- | --- | --- |
| Theme Title**Table 1.** Overview of thematic analysis structure: Core themes and sub-themes | Sub-theme title | Illustrative quote(s) |
| Theme 1.RESTRICTIONS | Anticipatory fear of deterioration | *I thought I’m not able…how fast it’s going to degenerate…I don’t want to be some person who’s sitting in a chair somewhere unable to move; and that sometimes makes me a bit anxious (ID1: Male, 53yrs, 11 tender & 8 swollen joints, PASI =10.4, systemic treatment)* |
| Fearing dependence on others | *I just worry about just the burden to my family and all that, that they have to look after me (ID17: Male, 49yrs, 6months since PsA onset, topical and systematic treatment)* |
| Limiting life course and life choices | *I've never had a boyfriend…I've, sort of, tended to avoid that sort of situation. (ID22: Female, 45yrs,29 years since PsA onset, topical, anti-inflammatory and biologic treatment)**I was invited to join, go to the college but I didn’t go because I couldn’t move or do anything, so I just stayed at home like a prisoner. (ID8: male, 27yrs, 16yrs since PsA onset, biologic treatment)* |
| Hopelessness | *I was saying to my brother the other day was that I wish when I was diagnosed with arthritis, I wish I’d come home and hung myself, to be quite honest (ID4: female, 44yrs, 29yrs since PsA onset, no treatment)* |
| Theme 2.ROLE OF OTHERS | Dismissed by other people | *Yes, I mean, the amount of people who say, oh there’s nothing wrong with you you’re a fraud, and that’s the hardest thing…you fucking live in my shoes for one day (ID10: female, 42yrs, 6yrs since PsA onset, anti-inflammatory and systemic treatment)* |
| Family blame / judgement  | *They told me I had deformed feet…My mother went mad. She swore it was me screwing my feet into shoes (ID11: female, 60yrs, 3yrs since PsA onset, biologic and anti-inflammatory treatment)**I’m not quite sure whether my partner or my son associates that with me being in pain, just thinks I’m being moody and snappy. (ID9: female, 41yrs, 20yrs since PsA onset, systemic treatment)* |
| Dismissed by healthcare professionals  | *It was as though my GP was fobbing me off; well take your Co-codamol. No I don’t want to. I want to know why it’s spreading…I really had to push for the referral to rheumatology, to anywhere, I had to push. (ID16: female, 44yrs, 4yrs since PsA onset, topical and anti-inflammatory treatment)* |
| Unprepared by healthcare  | *It does affect your life and they don’t tell you that, I was given nothing when I was first diagnosed, they never told me how I would feel, they never told me what my body would feel like. If I’d have had that at least I could have prepared myself (ID10: female, 42yrs, 6yrs since PsA onset, anti-inflammatory and systemic treatment)* |
| Theme 3.RESENTMENT | 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: male, 58yrs, 20 yrs since PsA onset, systemic and biologic treatment)* |
| Spoiled identity | *I’ve got a 21 year old son, and I’m thinking, when he has babies, am I going to be a proper grandma (ID16: female, 44yrs, 4yrs since PsA onset, topical and anti-inflammatory treatment)* |
| Premature aging | *But you just feel, you feel like an, well I feel like an old person, you know, it's awful.(ID15: female, 53yrs, 4yrs since PsA onset, systemic treatment)* |
| Social comparison: Envy | *And she’s got MS, but she’s less disabled than I am, and that’s what’s annoying.(ID4: female, 44yrs, 29yrs since PsA onset, no treatment)* |
| Theme 4. RESIGNATION | Brain versus body: Fighting the pain  | *Absolute agony and my brain’s telling me, stop, stop, but I’m thinking, no, the weather’s good, get some washing out (ID11: female, 60yrs, 3yrs since PsA onset, anti-inflammatory and biologic treatment)* |
| 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: female, 36yrs, 7yrs since PsA onset, anti-inflammatory and systemic treatment)* |
| Passive coping styles: Avoidance coping and emotional blocking  | *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...Just sleep, yeah, stay asleep for five or six days and wait until it subsides a bit. (ID13: male, 58yrs, 20 yrs since PsA onset, systemic and biologic treatment)**I sort of put up with it really…there’s no cure for it so I’ve thought I’ve got to live with it; so I haven’t come to the full conclusion of how to completely manage it (ID1: Male, 53yrs, 11 tender & 8 swollen joints, PASI =10.4, systemic treatment)* |