

Health professionals' perspectives on psychological distress and meeting patients' support needs in rheumatology care settings: A qualitative study

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Abstract

Background: Patients with inflammatory rheumatic diseases (IRDs) face challenges including pain, fatigue and disease flares. Evidence suggests their levels of anxiety and depression are higher compared to the general population. Rheumatology teams report psychologically distressed patients have additional support needs and require more clinical time. Little is currently known about models of support and their integration into care pathways.

Aim: To understand rheumatology health professionals' perspectives on patients' psychological distress and ways to meet support needs.

Methods: The study used a qualitative design, with data collected in telephone semi-structured interviews. Inductive thematic analysis was used to analyse the data.

Results: Fifteen interviews were conducted. Two main themes with sub-themes represent the data: Theme 1: 'No one shoe fits all'—the many manifestations of distress in patients (sub-themes: recognising distress, dealing with distress, dealing with life events alongside an IRD) and Theme 2: 'If rheumatology could be interwoven with psychological principles'—the need to attend to the psychological impact of IRDs, alongside the physical impact (sub-themes: priority given to physical health, working together to help patients in distress, how should patient distress be measured?, the need for extra time and resources).

Conclusion: Distress can be obvious or hidden, cause issues for patients and health professionals and lead to poor engagement with care provision. Health professionals described the powerful link between physical and mental distress. This study suggests psychological support provision should be embedded within the rheumatology team and that patients' emotional wellbeing should be given equal priority to their physical wellbeing.

KEYWORDS

health professionals, inflammatory rheumatic diseases, psychological distress, qualitative, support needs

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1 | INTRODUCTION

People with inflammatory rheumatic diseases (IRDs) face challenges including coping with pain, fatigue, flares of disease activity, complex medication regimens and decisions about when to seek clinical help with symptoms (Gettings, 2010; Homer, 2005). It has been estimated that up to 65% of people with IRDs also experience negative affective states including low mood, sorrow, irritability and worry (Geenen et al., 2012). A systematic review and meta-analysis for this population put the prevalence of major depressive disorder at 16.8%, similar to that observed in patients with diabetes, Parkinson's disease and cancer (Matcham et al., 2013). For individuals with rheumatoid arthritis, just a 10% reduction in the ability to perform activities they consider important may be followed by a sevenfold increase in depression over the subsequent year (Dickens et al., 2002). Another recent systematic review identified further associated risk factors for the prevalence of depression in rheumatoid arthritis (RA) patients, including functional impairments, muscle weakness, lack of social support, physical activity, alcohol/drug misuse, beliefs about the disease and cognitive impairment (Hou & Yang, 2020).

Across rheumatology patients, depression and anxiety are associated with increased long-term disease activity and physical disability, reduced odds of reaching remission at 2 years, and a 50% reduction in response to steroid treatment (Matcham et al., 2015, 2018). Distressed patients can also have poor medication adherence (Cabrera-Marroquín et al., 2014), resulting in frequent hospital admission and increased use of health resources (Jha et al., 2012; Sokol et al., 2005). The distress experienced by these patients may be a specific form of psychological distress attributed to the emotional response of living with long-term health conditions, also seen with cancer (Herschbach et al., 2004), diabetes (Dennick et al., 2015) and inflammatory bowel disease (Woodward et al., 2016). Indeed, a recent study found 'disease-specific distress' was experienced by people with RA and that this distress was distinct from clinical depression or anxiety disorders (Silke et al., 2021).

In the United Kingdom (UK), treatment and care of IRDs is provided by the multi-disciplinary team (MDT) in hospital rheumatology departments. MDTs typically include a rheumatologist (consultant or specialist trainee), specialist nurse, occupational therapist, physiotherapist and podiatrist. However, in a survey of UK rheumatology teams, only 17% had access to a full MDT with podiatrists particularly poorly represented (Ndosi et al., 2017). Psychologists (e.g., clinical, counselling and health psychologists) are rarely additional members of the MDT, despite the evidence of higher levels of anxiety and depression in people with IRDs compared to the general population (Isik et al., 2007) and despite current guidance to offer psychological interventions to help adults with RA adjust to living with their condition (NICE, 2020).

A lack of psychologists or support skills within the MDT therefore risks patients with psychological distress requiring extra resources from other members of the rheumatology team or living with the consequences of unmet needs. Patients may be dealing

with anxiety caused by living with an IRD alongside a variety of other issues, including other physical and mental health concerns, financial, relationship, work or family issues, which may all influence their medication adherence and their physical and social activity. Research with frequent attenders in hospital emergency departments identified a group of patients who were often psychologically and socially vulnerable in addition to experiencing health difficulties, and who reported high levels of worry and anxiety (Daniels et al., 2018) demonstrating the link between physical and mental distress and the need for psychological interventions.

The aim of the current study was to explore current clinical practices around identifying and supporting rheumatology patients who experience psychological distress from the perspective of rheumatology health professionals and to obtain their thoughts on acceptable models of psychological support provision.

2 | METHOD

2.1 | Study design

A qualitative design was used to explore health professionals' views about identifying and supporting patients with distress and their thoughts about psychological support provision. The data was collected using one-to-one, semi-structured, telephone interviews. Semi-structured interviews can generate insights into the thoughts and feelings of participants (DeJonckheere & Vaughn, 2019). In the semi-structured format, participants are asked the same core questions, but there is flexibility to probe more deeply and develop new lines of enquiry based on responses. The core questions in the interviews were based on an interview schedule designed by the research team, comprising researchers, patient research partners, two clinical psychologists and a rheumatology consultant (see Table 1 for interview schedule).

The study was approved by the Health and Applied Sciences Faculty Research Ethics Committee of the University of the West of England (reference: HAS.20.01.113).

TABLE 1 Interview schedule

Section 1: Experiences in practice

Definition of psychological distress in rheumatology patients

What distress looks like in rheumatology patients

- Signs and symptoms of distress
- Any similarities in backgrounds of patients and/or triggers for distress
- Response to patients experiencing distress

Section 2: Psychological support provision

Ideas on how to support distressed patients better in future

- Resources/interventions needed (individually and organisationally)
- Training/skills required
- Possible models of support

2.2 | Sampling and recruitment

Participants were rheumatology health professionals recruited from UK rheumatology teams who see patients that may have psychological distress. Participants were informed about the research and invited to take part through social media posts to professional bodies and networks (including the British Health Professionals in Rheumatology, the Bristol Bones and Joints Health Integration Team, the Royal College of Nursing Rheumatology Forum, the Royal College of Occupational Therapy Specialist Trauma and Musculoskeletal Health Section and the Musculoskeletal Association of Chartered Physiotherapists). A range of health professionals were invited, including nurses, physiotherapists, occupational therapists, podiatrists, psychologists and rheumatology consultants. Potential participants who were interested in taking part contacted the lead author for further information and to arrange a telephone interview.

2.3 | Data collection

Interviews were conducted over the telephone. Before the start of the interviews, health professionals signed a consent form and provided demographic data (type of clinical role in rheumatology, time in rheumatology clinical practice, gender and geographic location).

Interviews were conducted by the lead author, who had no prior relationship with the participants. Interviews were audio-recorded, transcribed by a professional transcription service, checked for accuracy against the original audio files and anonymised by changing the names of people and places.

Inductive thematic analysis was used to analyse the data (Braun & Clarke, 2013). This approach was taken as it is appropriate for research that is not based on pre-existing theory about the phenomena being studied. It was also suitable for highlighting both similarities and differences in the experiences and views of the participants. The lead author read all 15 transcripts and coded sections of text that related to the research question. Related clusters of coded text formed sub-themes, which were grouped together to form a smaller number of higher order themes that described broad elements in the dataset. A sub-set of seven anonymised transcripts were reviewed independently by five members of the study team (the Principal Investigator, two clinical psychologists and two patient research partners) and then discussed to ensure that the findings were informed by multiple viewpoints (Clarke & Braun, 2017). The final analysis was based on the integrated interpretations of all six team members.

3 | RESULTS

A total of 15 interviews were conducted with rheumatology health professionals including two rheumatology consultants, five nurses, four occupational therapists, one physiotherapist, one podiatrist and

two clinical psychologists. Interviews ranged from 25 to 65 min in length (median: 45 min). All the health professionals were female. Table S1 presents participant demographics. Two main themes with sub-themes represent the data (Table 2).

3.1 | Theme 1: 'No one shoe fits all'—The many manifestations of distress in patients

The health professionals described how patients with psychological distress can exhibit a range of symptoms, from tearfulness to anger or may show no outward signs at all and how their distress can fluctuate alongside life events. Health professionals reported varying in their abilities both to perceive and deal with patient distress. Table S2 presents some data excerpts evidencing theme 1 sub-themes.

3.2 | Sub-theme 1: Recognising distress

Some people will go very quiet, and some people will go very extrovert, some people will shout and swear, it's just extremely varied.

Interview 11, Nurse Specialist

Health professionals described how some patients find it challenging to cope with their diagnosis, treatments and symptoms such as pain and fatigue. Obvious signs of distress in patients described included crying, anger, defensiveness and fear, but distress could also be hidden and more difficult to notice. This was reported as patients who say they are feeling fine when their body-language says otherwise or patients who come across as 'difficult' or 'challenging'. In addition, health professionals differed in their perceptions of distress, with some relying on their 'gut instincts'. This highlights the current risk of patients not receiving the support they need when patients who are not clearly displaying their distress are seen by health professionals who are not trained to recognise it.

Figures varied for how many of their patients' the health professionals would characterise as having psychological distress, but for

TABLE 2 Themes and sub-themes

Main themes	Sub-themes
1. 'No one shoe fits all'—the many manifestations of distress in patients	<ol style="list-style-type: none"> 1. Recognising distress 2. Dealing with distress 3. Dealing with life events alongside an IRD
2. 'If rheumatology could be interwoven with psychological principles'—the need to attend to the psychological impact of IRDs, alongside the physical impact	<ol style="list-style-type: none"> 1. Priority given to physical health 2. Working together to help patients in distress 3. How should patient distress be measured? 4. The need for extra time and resources

the majority it was over 50% and figures were even higher for those health professionals working in more disadvantaged areas.

3.3 | Sub-theme 2: Dealing with distress

I had a sense of dread...thinking I am really out of my comfort zone now, what am I going to do?...I felt completely out of my depth.

Interview 14, Nurse Specialist

Distress, whether obvious or hidden, can cause issues for both patient and health professional and can lead to poor engagement. It can result in patients struggling to take on information as well as not sharing information in terms of what is happening in their lives, such as at home and work. Distress can result in poor adherence to medicines and the health consequences of this. Health professionals described how this can result in them feeling frustrated as they perceive that patients are not responding to their offers of help and support. Health professionals differed in their ability to deal with patients' distress, sometimes experiencing distress themselves if they did not feel equipped to manage the situations. Not all health professionals had received training in dealing with patients' distress and some had completed relevant training courses for example, Cognitive Behavioural Therapy in their own time as they were aware of their need for further skills. Improving health professionals' ability and confidence to deal with patients' distress for example, through specific training, supervision and education sessions would ultimately benefit both patient and health professional.

3.4 | Sub-theme 3: Dealing with life events alongside an IRD

They're trying to manage their own conditions, but they're also trying to manage life.

Interview 5, Physiotherapist

Health professionals reflected on how patients are dealing with symptoms such as pain and fatigue whilst trying to manage their daily life and had observed that levels of anxiety and depression varied according to patients' individual circumstances including age and employment status, support networks and co-morbidities. Health professionals commented on how patients are also dealing with issues that come with living with an invisible health condition as well as worries for the future. Some had observed how a diagnosis of an IRD had triggered past traumas from previous life events. The findings indicate that psychological support could be valuable to patients with regards to many kinds of decisions, such as starting a family and childcare, dealing with relationship breakdowns, having to change career or give up working completely.

3.5 | Theme 2: 'If Rheumatology could be interwoven with psychological principles'—The need to attend to the psychological impact of IRDs, alongside the physical impact

Health professionals described the inconsistency of support offered to patients with psychological distress and how future provision should ideally allow patients to be quickly and easily referred to psychological support when needed. They felt it was important that whoever provided this support had specialist knowledge of the distress that can be caused from living with a rheumatological condition and that the support would ideally be embedded within the team. They expressed their frustration with the current lack of time and resources to both provide and evaluate psychological support to reduce patients' distress. Table S3 presents some data excerpts evidencing theme 2 sub-themes.

3.6 | Sub-theme 1: Priority given to physical health

there's a lot of NICE guidance isn't there, about helping people with chronic conditions, but it's like in practice, we have this big divorce.

Interview 15, Nurse Specialist

Health professionals felt priority was given to physical health/symptoms. They described the powerful link between physical and psychological distress, the vicious cycle that can develop and described the benefits of incorporating a psychological approach to treatment, including increasing how often patients are asked about how they are feeling and how they are coping. It was felt a psychological approach could help patients with accepting their diagnosis and learning positive coping strategies. Health professionals described how patients can be in clinical remission, but still need help to psychologically adjust to their diagnosis, while other patients were unable or unwilling to take certain medications (e.g., due to side effects, personal beliefs/concerns, pregnancy) and needed help in dealing with this.

3.7 | Sub-theme 2: Working together to help patients in distress

...we want something that's very responsive and quite rapid...patients have discussed how they've called the Samaritans or they're calling 111 because they're in distress.

Interview 1, Podiatrist

Health professionals described their desire to be able to refer patients with psychological distress to psychological help more easily. One suggestion was the potential value of having a psychological support service within the hospital setting to help with all different

kinds of health conditions or comorbidities. Those health professionals who were in rheumatology teams that did have access to a psychologist were acutely aware of their lack of capacity to see all the patients requiring support. They also felt access to psychological support would benefit rheumatology health professionals through provision of supervision and training. Health professionals reflected that having psychological support embedded in the team could help to build strong and trusting relationships at times of vulnerability for both patients and health professionals.

3.8 | Sub-theme 3: How should patient distress be measured?

I'd like something much more tangible than my feeling that this patient is doing okay.

Interview 9, Occupational Therapist

Health professionals discussed the need to assess the value of support given to patients with psychological distress and how they would themselves value the reassurance of knowing their support had reduced patients' distress, but they were unsure on the most effective method of doing this. Many thought that demonstrating the efficacy of an intervention aimed at supporting patients with psychological distress would be challenging, because distress can so often be hidden or manifest in a range of emotions. They felt that useful areas to measure include coping, fatigue and confidence to self-manage their IRD. Alongside the use of measures, it would also be important to attend to visual cues that might indicate how someone is managing in their daily life. Most felt that asking the patient for feedback was essential. However, while health professionals were asking their patients how they were feeling and coping, replies were not being officially documented or routinely used for follow-up.

Health professionals had experience in using a variety of assessments including validated tools such as the Generalised Anxiety Disorder Assessment (GAD7)/Patient Health Questionnaire (PHQ-9)/Arthritis Helplessness Index (AHI)/Sickness Impact Profile (SIP)/Arthritis Impact Measurement Scale (AIMS)/Arthritis Self-Efficacy Scale (ASES)/the Distress Thermometer/Health Assessment Questionnaire (HAQ)/Disease Activity Score (DAS 28)/Hospital Anxiety and Depression Scale (HADS). However, despite their experience with these measures health professionals had often ceased to use them due to a lack of time (they stressed this was not due to the COVID-19 pandemic) and were keen to receive help in re-establishing their use or the use of another outcome measure.

3.9 | Sub-theme 4: The need for extra time and resources

What she really needed was to be heard, just reassurance, just to be held for a moment.

Interview 1, Podiatrist

The health professionals talked about their patients appreciating having time to talk and the difficulties they themselves experienced in having limited time for this. They reflected on the value expressed by patients of seeing physiotherapists and occupational therapists. These appointments are often longer and can provide an opportunity to talk and health professionals had observed how these appointments were often the first-time patients had been asked about how they are feeling. However, they were aware that there is often an element of chance to these appointment referrals and that some patients do not have this opportunity. Health professionals also mentioned that patient support groups (such as the Expert Patient Programme) had also often ceased running and they were keen for these to be re-established, though with limited resources they felt this would be difficult. It was felt that extra time for psychological support would benefit both patient and health professional and would be cost-effective due to improved patient outcomes.

The health professionals reflected on lessons learnt from COVID-19, such as the advantages and disadvantages of telephone and video appointments. Several referred to the future ideal support for patients incorporating a 'one-stop shop', or drop-in clinics as well as the value of introducing education groups for health professionals (e.g., on dealing with distress).

4 | DISCUSSION

This study set out to explore experiences and thoughts on identifying and supporting rheumatology patients with psychological distress from the perspective of rheumatology health professionals. The findings reflect the wide discrepancies with regards to psychological support available for these patients and highlighted the different ways in which patients present with distress. Health professionals discussed various measures that could help provide psychological support including raising awareness of the need for this support with other members of the MDT, ensuring more efficient referrals to support, providing training for health professionals, allowing time for support to be provided and measured and embedding support within the rheumatology team.

The study findings are consistent with research conducted by the National Rheumatoid Arthritis Society (Dures, Almeida, et al., 2014, 2016; Dures et al., 2017; NRAS, 2022) which found that three in four rheumatology units admit their mental health support needs to improve and that only one in five patients with arthritis report being asked about their mental health. Similarly, a British Society for Rheumatology (BSR) report (2021) found the rheumatology workforce lacks sufficient staff to provide the level of care recommended by NICE guidance and access to psychological support was found to be limited across all regions with 82% of adult rheumatology departments not having a psychologist embedded in their MDT.

For many patients, their rheumatological condition has led to them having profound lifestyle changes and medicine alone is not enough. While some health professionals had the skills and capacity to offer psychological support others had not received training to

recognise and deal with patients' distress and the rheumatology teams rarely included a practitioner psychologist (e.g., clinical, counselling or health). This has resulted in a huge variation in provision and leading to some distressed patients receiving support while others were going to their general practitioner for a counselling referral or calling the Samaritans. This situation risks patients suffering in silence, not knowing how, if or when they can get help.

The study findings are inconsistent with current guidance which recommends health professionals should consider psychological wellbeing when treating physical symptoms (Mental Health Foundation, 2019). The relationship between physical and mental health is often highly complex, symbiotic and bi-directional (Barber, 2020) and patients need a holistic approach as there is 'no health without mental health' (Department of Health, 2011). The health professionals in this study clearly indicated their awareness of the need for a consistent psychologically informed approach in the treatment of rheumatological conditions. Evidence exists for the effectiveness of therapies such as cognitive behavioural therapy (Evers et al., 2002; Navarrete-Navarrete et al., 2010; Sharpe et al., 2003; Sharpe & Schrieber, 2012) mindfulness (Mousavi et al., 2017) and psychoanalytic psychotherapy (Conceição et al., 2019) in reducing anxiety and depression and in learning skills to help make positive behaviour changes for patients with IRDs. However, evidence does not exist for this support being offered to all rheumatology patients with psychological distress and the health professionals all agreed this needs to change.

Health professionals recognised that being diagnosed and living with a rheumatological condition can affect patients' self-confidence and ability to self-manage. To achieve the best arthritis care, patients need to work with their healthcare team (Dures, Hewlett, et al., 2014, 2016) to find the right combination of medication, therapy and exercise and must be given the opportunity to take part in educational activities, including self-management programmes, to empower them to be more involved in shared decision making, to better manage pain, disease flares and fatigue and to improve their quality of life (NICE, 2022). This makes the health professionals' experiences that patient support groups had often ceased running rather than increased in number even more concerning.

Health professionals' experiences also highlighted the importance of issues such as patient adherence and managing patient expectations. With inadequate time and resources to provide the support patients need the opportunities for a collaborative relationship are reduced and patient expectations are unlikely to be met with negative consequences on adherence to treatment plans and worse outcomes for both patient health and the healthcare system. Research indicates patients are more likely to adhere to treatment and to be satisfied with their care if they feel that health professionals are respectful, interested, supportive and understanding (Miller & Rollnick, 1991). The health professionals' experiences reflect how difficult it is for them to show the required level of support and understanding with inadequate time and resources.

This study has also indicated the effect on the health professionals themselves of dealing with patients' distress, with some

feeling ill equipped and being left exhausted, frustrated, vulnerable and anxious. Health professionals must be given the time and support to follow the guidance as advised and to look after both their own and their patients' health. Emotionally exhausted clinicians have been shown to be less vigilant and more likely to make errors (Welp et al., 2016).

Financial considerations may prohibit the inclusion of practitioner psychologists within every rheumatology department. However, embedding a psychologically informed approach within rheumatology teams would enable patients to become more effective at self-management resulting in less need for follow-up care, less calls to rheumatology helplines, shorter appointments, less need for primary care and fewer medicines. This in turn could reduce National health service (NHS) costs—it has been projected that at least £1 in every £8 spent by the NHS on long-term conditions is linked to poor mental health and wellbeing (Naylor et al., 2012). With one in 10 employees in the UK reporting having a musculoskeletal problem (PublicHealth England, 2019) ensuring resources are made available for individuals to receive all the support they need, including psychological support, is crucial not only for their own health and wellbeing and but also for the wider economy.

Future research should investigate the most appropriate method to integrate psychological support into rheumatology care pathways and whether this should be using existing interventions, a novel intervention or the design of a new care pathway to include an intervention for distressed patients. Further research needs to investigate the effectiveness of different treatment methods on different groups of people including age, gender, employment and individual priorities. This would allow the intervention to be specifically targeted and tailored to different group's needs.

4.1 | Strengths and limitations

A strength of this study is participants' varied professional backgrounds, including rheumatology consultants, nurses, occupational therapists, physiotherapists, a podiatrist and clinical psychologists. Participants' experiences were based on working in a variety of environments as they worked in several different hospital trusts with varying work practices, team structures and resources. Participants were able to talk first-hand about their experience of dealing with patients' distress and to describe the effect on themselves as well as the effects they had witnessed on some of their patients and colleagues which would not routinely be captured elsewhere. Participants provided thoughts on how best to provide and assess support based on their experience of working closely with distressed patients. The data was analysed by team members with varied backgrounds, including, academics, clinical psychologists, a consultant rheumatologist and patient partners with first-hand experience of being treated for a rheumatic condition. A limitation of this study is that the views and experiences of the patients themselves are not included and so a further study will address this as the patient perspective on future psychological support provision is paramount to ensure maximum

benefit. Also, all the participants were female. The research was conducted during the height of the COVID-19 pandemic, which might have impacted recruitment as well as participants' perceptions and experiences at the time due to heightened stress and workloads.

5 | CONCLUSIONS

Distress can be obvious or hidden, cause issues for patient and health professional and can lead to poor engagement with care provision. While all the health professionals in this study had experienced dealing with patients' distress, they did not have equal access to training, supervision or the ability to refer their patients to psychological support. This highlights current variation in the provision of support for distressed patients. The health professionals described the powerful link between physical and mental distress and the benefits of incorporating a psychologically informed approach into treatment. They felt strongly that the emotional wellbeing of patients should be considered an equal priority to their physical wellbeing and shared their frustrations at how a lack of resources and services under pressure were obstructing this. The study suggests psychological support should become more embedded within rheumatology teams for the benefit of patients, staff and service outcomes alike.

AUTHOR CONTRIBUTIONS

Initial concept—Emma Dures. Study design/method—Emma Dures, Jo Daniels, Miles Thompson, Joanna C. Robson, Mwidimi Ndos, Caroline Swales, Kate Wilkins. Access to participants—Emma Dures, Mwidimi Ndos, Joanna C. Robson. Topic guide—Christine Silverthorne, Emma Dures, Miles Thompson. Interviews—Christine Silverthorne. Analysis—All, led by Christine Silverthorne. Project management—Emma Dures. Draughting—Christine Silverthorne. Reviewing—All.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.



DATA AVAILABILITY STATEMENT

No data are available. This study involved analysis of qualitative data therefore the data generated are not suitable for sharing beyond that contained within the report.

ETHICS STATEMENT

The study was approved by the Health and Applied Sciences Faculty Research Ethics Committee of the University of the West of England (reference: HAS.20.01.113).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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