RESEARCH ARTICLE

Patients' Perspectives on the Psychological Impact of Inflammatory Arthritis and Meeting the Associated Support Needs: Open-Ended Responses in a Multi-Centre Survey

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Abstract

Objectives. Psychological support for inflammatory arthritis is recommended in rheumatology treatment guidelines. Previous research found that high numbers of patients would access such support but that provision is often inconsistent and inadequate. The present study explored patients' perspectives on the nature of the psychological impact of inflammatory arthritis and how to meet the associated support needs.

Methods. A cross-sectional survey was conducted, using questionnaires which included three open-ended questions about helpful and unhelpful psychological support. The questionnaires were administered to 1,080 patients at six regional rheumatology units across England, and 1,200 members of a national patient charity.

Results. A total of 1,210 (53%) patients completed the questionnaire, with 779 (64%) responding to the open-ended questions: 80% female; mean age 59 years (12.6); disease duration <5 years (40%), 5–10 years (20%), >10 years (40%). Data were analysed using a hybrid content analysis. Four categories emerged: challenges of an altered life course (negative emotions, isolation and loneliness, a dysfunctional body, loss, strained relationships, and fears for the future); poor communication (feeling unheard, clinicians' reluctance to address psychological issues, a lack of help to manage pain and fatigue, and struggling to ask for help); understood by others (sharing with people who have arthritis, supportive family and friends, whole team support, and understanding from clinicians); and acquiring strategies (ways of coping).

Conclusions. Psychological distress was commonplace, and often attributed to fatigue and pain. In addition to peers and family, patients looked to the rheumatology team for validation and support. Further research will address the skills training needs of rheumatology teams to meet patients' psychological support requirements.

Keywords

Inflammatory arthritis; psychological support; patient perspective; fatigue; pain

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Introduction

It is estimated that one in 12 women and one in 20 men will develop a form of inflammatory arthritis (IA) during their lifetime, with the most common being rheumatoid arthritis (RA) (Crowson et al., 2011). IA is a long-term condition that requires patients to make behaviour changes and psychological adjustments to manage the impact of the condition

on their lives. Challenges include managing fluctuating pain, fatigue and flares of disease activity, disability and emotional consequences (Homer, 2005). Recent research in ≥1,200 patients with IA found that large numbers struggle to meet these challenges, with 82% reporting that they wanted support to manage the impact of pain and fatigue, 57% to manage emotions and 34% to address depression (Dures et al., 2016).

The psychological needs resulting from physical symptoms in long-term conditions have been conceptualized in a five-level pyramid (Fellow-Smith et al., 2012). At the base, level 1 describes general difficulties in coping and the perceived consequences for the patient's lifestyle and relationships. These are problems common to many people with this condition. At the top, level 5 describes mental illness that is severe, requires specialist interventions and affects far fewer patients. There is evidence of varying levels of psychological need among patients with IA. At a lower level, the incidence of negative affective states which do not reach clinical cut-offs, such as low mood, sorrow, insomnia, irritability and worry, are estimated to be as high as 65% (Geenen et al., 2012). At a higher level, a recent systematic review and meta-analysis put the prevalence of major depressive disorder at 16.8% (Matcham et al., 2013), higher than in the general population (Waraich et al., 2004).

It is recognized that patients may have needs represented at several levels simultaneously. For example, someone with severe mental illness (level 5) may also have anxiety (level 1) about an aspect of managing their IA. Patients may also move up or down the levels of need at different points in their life, with management of the physical illness, life events or a change in circumstances. For example, recent longitudinal research with a sample of patients with early RA found that at baseline, 46.9% screened as positive for psychological distress. Over three years, psychological distress decreased significantly, with a prevalence of 25.8% at 36 months (Bacconnier et al., 2015). The prevalence of psychological distress among patients with IA is important because it is associated with lower quality of life, poorer objective and subjective health outcomes, and higher costs and use of healthcare resources (DiMatteo et al., 2000; Englbrecht et al., 2012; Joyce et al., 2009; Sleath et al., 2008;). It has been argued that improved support for common mental health problems in long-term conditions could achieve substantial population health gain in terms of reducing severe disability, and extending healthy life expectancy and occupational functioning (Weich et al., 2013). Within IA, there is recent evidence that depression and anxiety symptoms are associated with increased long-term disease activity and physical disability, reduced odds of reaching remission at two years, and a 50% reduction in response to prednisolone (a widely used steroid treatment) (Matcham et al., 2016).

Evidence suggests that the psychological consequences of IA are amenable to change and that psychological interventions can be important adjunctive therapies in the medical management of the condition (Astin et al., 2002; Keefe and Somers, 2010; Knittle et al., 2010). European and UK treatment guidelines and the National Institute for Health and Care Excellence (NICE) recommend that patients with RA are offered psychological interventions as part of multidisciplinary care (Luqmani et al., 2006, 2009; Forestier et al., 2009; National Institute for Health and Care Excellence, 2009). However, the psychological support available is 'inconsistent and haphazard' (Gettings, 2010). A national survey of rheumatology units in England found that 73% rated their provision as inadequate, and only 4% as good (Dures et al., 2014). While there is strong evidence of varying levels of psychological distress in relation to living with IA, little is known about patients' perspectives on how the associated support needs should be met. The present study explored patients' views and experiences on psychological support for their IA.

Methods

Study design and ethics approval

The study team, comprising researchers, patient partners and rheumatology and psychology clinicians, designed a questionnaire as part of a larger study to scope patient preferences for psychological support in IA. The team agreed on questions addressing personal experience of social and emotional support received from the rheumatology team and patient preferences for psychological support. Closed questions asked patients about the type of service, provider, mode of delivery and aspects of IA that they would like support services to address. These data have been reported in a previous publication (Dures et al., 2016). In addition to the closed questions, open questions were included at the end of the questionnaire, to give participants an opportunity to write about their views and experiences

in their own words. Three questions asked about examples of helpful and unhelpful psychological support and about any other views or experiences relating to the social or emotional impact of IA. Half a page of A4 was allocated per open-ended question, to encourage detailed responses and the generation of depth data (O'Cathain and Thomas, 2004).

The questionnaire was piloted with six patients, to check that it was clear, comprehensive, relevant and meaningful. The feedback indicated that there were no problems. Ethics approval was obtained from the NRES Committee North East, County Durham and Tees Valley (REC reference: 12/NE/0272).

Participants and data collection

To capture a range of views, participants were recruited through a national patient RA charity and rheumatology units in six regional hospitals across England, selected to reflect diverse geographical locations and serving differing communities in relation to urbanity/rurality and socioeconomic makeup. The patient charity mailed the questionnaire to 1,200 patients selected randomly from their membership database, and subsequently placed a generic reminder in an electronic newsletter. At the six regional hospitals, a member of the local team handed out 180 packs (containing an invitation letter, a patient information sheet and a questionnaire) to consecutive patients attending outpatient appointments, and mailed a reminder approximately two weeks later. The eligibility criteria comprised patients over 18 years of age with a diagnosis of a form of IA and either being a member of the patient charity or attending an outpatient appointment at one of the collaborating hospital sites. Questionnaires were completed anonymously and returned directly to the research team.

Analysis

Each questionnaire had an identifier denoting the rheumatology unit or patient charity that had administered the pack, and its number within that batch. Participants' written responses to the open-ended questions were typed into an Excel spreadsheet. A hybrid qualitative content analysis was used to code data in two phases: an inductive content analysis followed by a deductive content analysis (Hsieh and Shannon, 2005). The analysis of the written responses was extended beyond the manifest content (e.g. observable features such as key words) to include interpretations of the latent meaning (Kondracki et al., 2002). Analysis began with open-coding of participants' written words or sentences. Codes that shared a similar meaning into sub-categories were grouped. The number of sub-categories was then reduced by integrating those that were conceptually similar, and re-grouping them under higher-level main categories, creating a two-level hierarchy (Elo and Kyngäs, 2008). This phase was conducted manually by two members of the research team, who each coded and categorized the full data set independently.

When both researchers had completed their inductive analysis, they shared their workings and interpretations of the data with the study team. This informed the development of a framework to guide a deductive analysis and verify phase 1 data interpretation. The framework comprised labels and descriptions of the main categories plus sub-categories exemplified by data excerpts. Four members of the research team who had not been involved in the inductive analysis independently analysed sub-sets of the data using the framework. This was an iterative process, with proposed amendments to the framework discussed at study team meetings. Results are based on the third iteration of the framework.

Results

A total of 1,210 (53%) patients completed the questionnaire. Of these, 779 (64%) responded to the open-ended questions: 80% female; mean age 59 years (12.6); disease duration <5 years (40%), 5–10 years (20%), >10 years (40%). The length of participants' open-ended responses varied from a single sentence to several paragraphs, with the majority of responses being 150–200 words between the three questions. Four main categories emerged during analysis, made up of sub-categories evidenced by data excerpts. For context, we have provided information on the participant's gender (M = male, F = female), age (in years) and disease duration category after each excerpt below.

Category 1: Challenges of an altered life course

Participants' experiences of psychological support were set in the context of the psychological consequences of IA, and expressions of distress and struggle were

commonplace. Challenges ranged from dealing with restrictive symptoms on a daily basis to experiencing multiple losses over time. Responses captured the impact of an altered life course at intra-individual and inter-individual levels.

Negative emotions

Participants described a range of negative emotions in response to their IA, including anger, frustration and sorrow. These feelings could be overwhelming at times, and for some participants they were linked to experiences of depression:

'I have so much anger due to my arthritis and frustration; I cannot run with my grandchildren and that is heart breaking'. [F, 53, <5 years]

'This has affected me physically, career-wise, emotionally, and I have depression and anxiety; I didn't feel prepared for the impact of this condition'. [F, 35, <5 years]

'Depression, frustration, self-worth. Physical limitations – i.e. can't be my old self (DIY, weight lifting, fun activities – participation)'. [M, 51, >10 years]

Isolation and loneliness

Participants often felt that their IA set them apart from peers and increased their vulnerability to social isolation and loneliness. This was brought about by their withdrawal from, or loss of, social activities and the perception that other people could not understand the consequences of IA:

'I feel alone and fail to see any hope'. [F, 24, <5 years]

'It is a very lonely illness. It stops me from joining in activities that I would enjoy and it is far from easy to explain to people'. [F, 65, 5–10 years]

'Nobody understands RA – the side effects of the illness and drugs, the impact it has on relationships. It's a sad, lonely illness'. [F, 42, >10 years]

A dysfunctional body

Another source of unhappiness was the sense of a dysfunctional body, with an altered appearance and reduced function. This had a negative impact on body image, mobility and flexibility, and caused sexual difficulties:

'I find the most depressing thing is body changes – be it swelling up from steroid intake, swollen waist/stomach that nothing will shift, thin bony shoulders, bad feet despite seeing podiatrists for years on a regular basis etc. Even if the pain subsides a bit, I just feel a mess in general but nobody seems to think how depressing this can be'. [F, 71, >10 years]

'Even though I have been married to my husband for 32 years and we love each other very much, our sex life has suffered because my whole body hurts and is so sensitive/painful to touch as well as the fact that I have little mobility and flexibility. Before this problem, I ran, worked out, did step- and keep-fit classes, and danced a lot. All of this is a thing of the past and very depressing'. [F, 55, <5 years]

Strained relationships

Participants described their relationships becoming strained as a result of the symptoms of IA and the ways in which they and their spouses/partners responded to the condition:

'The lack of understanding and emotional support from my husband was and is distressing. Leading up to, and at the time of being diagnosed with RA, I was having a lot of periods of intense pain and stiffness. I felt unable to honour some of our social engagements – this was met by grumpiness and complaints that I constrained him. Since the first severe symptoms of RA appeared, he has only once asked me how I am feeling'. [F, 48, <5 years]

'Relationship with my wife very strained now, probably to do with me not coping very well with this disease, always feeling very tired, unable to sleep properly, being tired, teary etc., and trying

to run an electrical business at same time'. [M, 46, 5–10 years]

'*I found when the pain is bad I snap and am grumpy with other members of my household, which puts a big strain on relationships. I also find it increasingly frustrating not being able to do jobs and things that I used to do*'. [M, 66, <5 years]

Loss

For many participants, the losses were multiple, and affected their sense of identity, self-confidence and valued roles. Among some participants there was grief for the loss of the life they had been living prior to the onset of their IA:

'*I have lost all my confidence in myself, my capabilities and looks… I feel terrible about how this has impacted on my husband and child, and frequently think they would be better off without me*'. [F, 36, <5 years]

'*The emotional impact of RA is huge. I lost the job I loved and worked many years to achieve the post I held – I was devastated*'. [F, 63, 5–10 years]

'*Over time, if individuals are supported they can deal with all these emotions and be able to get on with life – after they have fully grieved for what has gone/been lost. It's like a bereavement for your old life*'. [F, 42, <5 years]

'*Frustration and anger at growing independence loss*'. [M, 63, <5 years]

Fear about the future

Reflecting on what might lie ahead could prompt fears related to negative beliefs about disease progression and increasing disability, and anxiety about how to manage daily tasks in the long term:

'*Very isolating and frightening. What is going to happen to me – but I know that no one can answer that*'. [F, 47, 5-10 years]

'*I am frightened about the future and what it is going to be like for me. I do not want to sound selfish and I do not just sit round and take it. I get up and say, no, it will not get me, but I do have lots of black moments*'. [M, 60, 5–10 years]

'*I am worried about how long I can keep going, have no idea who to speak to about it all, can get quite depressed and isolated as I don't want to burden family and friends with my concerns*'. [F, 49, <5 years]

Category 2: Poor communication

The quality and focus of interactions with clinicians were influential in patients feeling psychologically supported, with poor communication identified as a major barrier to helpful support:

Feeling unheard

Participants described feeling unheard and consequently alone when they could not make contact with the clinical team, or their interactions were unsatisfactory:

'*The clinics do not give the allowed time for the patient who may want to talk about issues*'. [M, 56, <5 years]

'*I consistently feel patronized, unimportant and never listened to*'. [F, 51, <5 years]

'*No-one has either the time or inclination to either answer my questions or have any time to listen to me*'. [F, 39, >10 years]

'*I had to cope on my own; I didn't feel I could speak to consultant/nurse about my problems as it was always rushed/lacking time and the right questions never asked*'. [F, 43, >10 years]

Clinicians' reluctance to address psychological issues

Specifically, participants described how some clinicians appeared reluctant to address social and

emotional issues, preferring to focus solely on physical 'problems' or aspects of medical management during consultations. Such behaviour by clinicians could make participants feel as though their emotional responses were unacceptable, inappropriate and not the concern of the rheumatology team:

> *'I have noticed that when emotional problems are mentioned in the rheumatology dept. they tend to be ignored, concentrating more on physical well-being'*. [M, 52, <5 years]

> *'I don't think these aspects concern the professionals. I've never once in 3½ years been asked how I'm coping'*. [F, 59, <5 years]

> *'I have broken down twice in the RA clinic this past 12 months. The clinician seemed embarrassed – unable to cope with my emotional state'*. [F, 42, >10 years]

> *'The social and emotional impact of RA could be given equal importance to physical monitoring – i.e. DAS scoring. In my opinion, the emotional impact has a considerable influence on pain and general well-being. This could be clarified with patients as acceptable rather than them feeling they are not coping and sweeping these issues "under the carpet"'*. [F, 71, >10 years]

A lack of help to manage pain and fatigue

Participants often attributed their psychological distress to the impact of IA-related pain and fatigue. Clinicians' failure to acknowledge and validate pain and fatigue could exacerbate participants' psychological distress and undermine their confidence to manage their effects:

> *'The dismissing of fatigue as "part of the disease process" early after diagnosis – failed to validate the real impact on all aspects of one's life, of flattening fatigue. Social, emotional and financial'*. [F, 53, > 10 years]

> *'The pain was constant. I could not sleep properly and my ability to get about and do things got worse and I felt as though no one and nothing was helping, and got very depressed and angry'*. [M, 76, >10 years]

> *'The effect of fatigue is largely ignored. One loses confidence, the ability to commit to anything, and it can completely change one's personality'*. [F, 69, >10 years]

Finding it hard to ask for help

As well as identifying the role of clinicians' behaviour and communication, there were participants who acknowledged their own reluctance to discuss the negative emotional impact of IA. For some, the difficulty of asking for help indicated a preference to manage on their own, but for others it was a barrier to receiving support that they believed could be useful:

> *'I have not requested help for emotional needs. I find it hard to ask for help with anything physical or emotional'*. [F, 54, <5 years]

> *'I am more and more isolated and really need more and more support but I have a very strange way of asking for help – never with a "please" or a "thank you" – I don't know how to be nice anymore! I'm so full of anger and pain'*. [F, 57, <5 years]

> *'By nature, I am a person that likes to come to terms with my own situation and I am not comfortable seeking social or emotional support'*. [M, 66, <5 years]

Category 3: Understood by others

Participants drew on a range of external and internal resources to manage the impact of their IA. Feeling understood by others was central to feeling psychologically supported.

Supportive family and friends

The emotional, social and practical help provided by informal networks of family and friends was highly valued by many participants:

'*Brother/friends/church fellowship – excellent support – practical, social and emotional. Positive feeling someone available if required (not alone or isolated), always someone to talk to/share with if needed*'. [F, 50, <5 years]

'*Support from my family/friends is essential and I couldn't function without it; from talking to help with daily living tasks during a flare*'. [F, 45, >10 years]

'*Friends have been a life line. I telephone friends more than previously … sympathetic, sensible, wise people*'. [F, 80, >5 years]

Sharing with people who have arthritis

Communicating with other people who had IA, to share experiences and information, enabled many participants to feel reassured, connected and less alone:

'*Just being able to share experiences with someone in a similar situation helps*'. [M, 30, >10 years]

'*Talking to other patients at group hydrotherapy, and even sometimes in the waiting room. Sometimes it is better speaking to someone who lives with the condition, and who has experienced the exact same conditions and feelings that you have. It's reassuring to know you're not the only one*'. [M, 42, <5 years]

'*Support groups and information online is good*'. [F, 46, <5 years]

Team support

The rheumatology team was an important source of support, with participants highlighting the benefits of building a long-term relationship with clinicians who were able to normalize what could be an overwhelming emotional response to their IA:

'*I have found it drags me down. I have always found the rheumatology team to be supportive, kind and considerate, and nothing is too much trouble*'. [M, 57, <5 years]

'*The rheumatology team have been amazing and very understanding. As at first, I was very emotional and did not understand what was happening to me. They made me aware that these things were my new" illness and it was normal for RA. They were brilliant*'. [F, 43, <5 years]

'*The team at the unit have been very helpful, especially the helpline to specialist nurses, who have been excellent. Since visiting the unit, I was diagnosed with RA last October 2012, and have found the whole unit very caring and helpful*'. *[F, 62, <5 years]*

Understanding from clinicians

In addition, there was the positive impact of individual clinicians who demonstrated understanding, and whose understanding and intervention facilitated adjustment to living with a long-term condition:

'*A few years ago, my rheumatology nurse helped me come to terms with the fact that I am restricted physically – i.e. I may never run again or walk for miles. She understood the fatigue experienced holding down a full-time job and being a single parent*'. [F, 66, >10 years]

'*I was fortunate to be referred by my rheumatology nurse specialist to a counsellor who specifically worked with patients managing chronic disease. This helped me through those dark days as I felt she had time to listen and understand my emotions and practical frustrations*'. [F, 53, >10 years]

'*The support of the consultant at the hospital. Having a name put to my illness was actually helpful. Being believed and listened to*'. [F, 59, >10 years]

'*Have had help with talking about emotions with rheumatology nurse as I sometimes find it hard to express how it affects me*'. [M, 44, <5 years]

Category 4: Acquiring strategies

Some participants described constructive ways of coping with the psychological impact of their IA. Although the means by which they acquired their strategies were not always clear in the data, they provided insights into a range of behavioural, cognitive and emotional approaches that they found helpful:

Ways of coping

'I had the opportunity to take part in a pain management trial. It involved cognitive therapy. This was probably the first time I was actually asked how I felt emotionally with the disease. I have learned to prioritize my day and talk about my emotions with my family'. [F, 43, >10 years]

'I've experimented with meditation techniques (e.g. mindfulness meditation and "Soto Zen") and found this really helpful in calming, reducing stress and therefore symptoms'. [M, 55, >10 years]

'I swim 4× a week, use jacuzzi, walk every day. When I did Tai Chi I found it excellent for mobility of joints… I try to be responsible for my health and eat well but do not get overweight. I exercise both body and mind and keep positive. If I have a flare up, I know it will pass, so rest for a few days and start living again'. [F, 77, >10 years]

'I found the booklets in my rheumatology dept. explain a lot of issues clearly and are very informative; they helped me understand my condition, which helped me cope better'. [F, 58, <5 years]

Discussion

The present study found that the psychological consequences of IA were both wide-ranging and profound, and that participants' experiences of support were mixed. Interactions with the clinical team could influence participants' psychological status. Distress could be exacerbated if participants perceived the clinical team to be unwilling or unable to acknowledge the emotional and social challenges that they were having to address. By contrast, interactions characterized by validation of the impact of IA could reduce reports of psychological distress and facilitate adaptation and self-management.

Our study supports and extends previous research findings that IA can have a negative impact on patients' quality of life, with detrimental effects occurring at both an individual level (for example, anxiety, depression and poor body image) (Jorge et al., 2010; Covic et al., 2012) and at an inter-individual level (for example, reduced participation and social well-being, and social isolation) (Neugebauer and Katz, 2004; Backman, 2006). In addition to insights on the nature of the psychological impact of IA, these findings capture patients' perspectives on how to meet the associated support needs. Participants in the present study often attributed their psychological distress to the impact of pain and fatigue. Previously, a large cohort study found that pain was the most important predictor of psychosocial health in patients with RA, explaining approximately 44% of the observed variance (Courvoisier et al., 2012). In a sample of patients with RA and osteoarthritis (OA), those with greater pain disability experienced heightened psychological distress and lower disease self-efficacy (patients' perceptions of their ability to cope with the consequences of their IA) (James et al., 2005). While the relationship of fatigue to demographic and clinical variables in IA has been less widely researched and is therefore less established, it is increasingly recognized as a symptom that affects large numbers of patients, is a challenge to manage and can have a significant impact on well-being (Rupp *et al.*, 2004; Hewlett et al., 2005; Repping-Wuts et al., 2009). The present study provides further evidence that clinical teams should extend their focus beyond disease activity and measures of disability, and attend to how patients are managing the impact of pain and fatigue.

Addressing the impact of IA as part of routine care would be helpful in meeting the psychological needs resulting from physical symptoms in long-term conditions at level 1.

It is proposed that level 1 needs can be met by healthcare professionals after basic training, and without support from a psychologist; level 2 needs should be met by healthcare professionals with low-intensity psychology training (e.g. nurses who have completed a course of cognitive-behavioural approaches); levels 3 and 4 needs require support from clinical psychologists, while level 5 conditions require psychiatrists. This has implications for the attitudes, skills and confidence

of rheumatology clinicians towards incorporating a range of psychologically informed techniques into their consultations. These could include motivational interviewing to identify patients' health beliefs and priorities (Marks et al., 2005; Rollnick et al., 2010), and cognitive-behavioural techniques to help patients to identify links between their symptoms, thoughts and feelings, and how these are driving their behaviours (White, 2001; Sage et al., 2008). Although some clinicians are likely to have undertaken generic communication skills training, evidence from across the medical sphere shows that many skills are not put into practice (Ha and Longdecker, 2010). One reason is a reluctance to discuss the social and emotional impact of the health condition, owing to concerns about increasing patients' distress or taking up too much time in the consultation (Maguire and Pitceathly, 2002). However, randomized controlled trials involving clinicians working on specific health conditions suggest that skills training can be helpful. Examples include patient-centred skills training for gastroenterology clinicians and cognitive-behavioural skills training for palliative care nurses (Kennedy et al., 2004; Mannix et al., 2006). There is a now a need for research to establish the skills training needs of rheumatology clinicians and teams.

In addition to the influence of interactions in the consultation, participants identified the advantages of sharing experiences with other patients who have the same condition. Given participants' increased vulnerability to social isolation as a consequence of their IA, social support is likely to be valuable. A recent population-based study established the importance of social participation for positive mental health (Theis et al., 2013), while a four-year prospective study concluded that early provision of social support interventions might help to decrease mental health problems in patients at risk of depression (Benka et al., 2014). One way that clinical teams might facilitate patients sharing experiences in a supportive environment is through the provision of condition-specific group self-management programmes. For example, a programme to reduce the impact of fatigue has been shown to support patients' psychological adjustment to their IA, including the incorporation of valued activities into daily life (Hewlett et al., 2011; Dures et al., 2012).

Strengths of the present study included the sample size and the range of patients who described their experiences and views in their own words, generating a large and novel data set. However, there are considerations to take into account with open-ended questions in a questionnaire. The preceding closed questions might have influenced responses to the open-ended questions and imposed constraints on what participants perceived as legitimate and relevant. Compared with qualitative data collected through interactions between participants and researchers, there was less context and detail in individual accounts. The lack of interaction also meant that the researchers could not follow up or clarify responses with participants. However, there can also be advantages of not using face-to-face methods; for example, data might be less affected by social desirability and inhibition. This could lead to participants being more open about the topic being studied and having more time to reflect on their responses (Richards and Emslie, 2000; Nunkoosing, 2005).

Conclusions

Reports of high levels of psychological distress were commonplace among patients with IA and often attributed to the impact of pain and fatigue. The consequences included negative emotional responses, including depression, and withdrawal from social interactions, leading to loneliness and isolation. In addition to valuing the support of family and friends, patients looked to the rheumatology team to acknowledge the psychological impact of their IA. Although this was often not provided, when it was offered, patients identified clinicians' understanding and signposting to appropriate support as helpful. The influence of interaction with clinicians on patients' psychological status highlights the importance of addressing the skills training needs of rheumatology teams to discuss the social and emotional impact of IA.

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