Acceptability of a brief fatigue intervention for inflammatory arthritis: a qualitative process evaluation

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Abstract:

Objectives. We developed a brief cognitive-behavioural, one-to-one intervention to reduce fatigue impact for patients with inflammatory arthritis. This qualitative process evaluation explored intervention acceptability and potential refinements from the perspective of (i) patients who attended sessions and (ii) rheumatology health professionals (RHPs) who delivered the intervention.

Methods. Interviews were conducted with patients and RHPs from five NHS sites. Data were analysed using inductive thematic analysis.

Results. Twenty-two patients and eleven RHPs participated. Patient themes: Collaborative, non-judgemental consultations: patients valued having space to reflect, where their fatigue was validated. Relevant content, but not ground-breaking: patients appreciated the opportunity to tailor content to individual priorities. Daily diaries were useful to visualise fatigue. Self-awareness: patients reported increased acceptance, sense of control, and confidence to manage fatigue. Degrees of openness to change: sessions prompted patients to engage in behaviour change. For some, complicated lives made it difficult to plan for change. RHP themes: Engagement with intervention: RHPs liked training face-to-face, and sessions were more enjoyable with experience of delivery. Research versus clinical practice: RHPs expressed concern about fitting sessions into NHS clinic appointments. It was difficult to offer follow-up sessions within two-weeks. Collaborating with patients: RHPs reported that patients engaged with the tools and strategies. Some RHPs followed the manual in a linear way, others used it flexibly.

Conclusions. There is potential for this brief fatigue intervention to benefit patients. Future research will focus on flexibility to fit with local services and creating educational resources to use in a range of contexts.

Key words: fatigue, inflammatory arthritis, cognitive-behavioural, process evaluation, acceptability, brief intervention, self-efficacy, rheumatology

Key messages:
1. Patients valued the collaborative, therapeutic approach of sessions, describing increased feelings of acceptance and control.
2. RHPs liked and enjoyed delivering the sessions, but it was difficult to fit into clinics.
3. Potential refinements include developing content that can be applied in varying contexts and formats.
Lay summary

What does this mean for patients?

This purpose of this study was to find out what patients and health professionals thought about taking part in fatigue management sessions for people with inflammatory arthritis. We discussed the sessions with 22 patients who attended sessions, and eight health professionals who were trained in and delivered the sessions. Patients told us that they liked having an opportunity to talk about their fatigue. Although the information was not always new, they liked the resources, including the daily diaries. Sessions made them think about things in their day-to-day lives that might be making their fatigue worse. For some, it gave them ideas about things to change or do differently. Health professionals liked training with other health professionals and felt more confident about the fatigue sessions with practise. Some were using the fatigue information and resources in their usual consultations. Sometimes it was difficult to make sure everyone had enough time, and to fit in all the appointments within the recommended two-week time frame. The results show that patients value the opportunity to address their fatigue with a health professional, but also the challenges of providing these sessions in clinical practice.

Introduction

Fatigue is a common, overwhelming, and unpredictable symptom in inflammatory arthritis (IA) (1,2), likely to be caused by the complex interaction of clinical factors (e.g. inflammation, pain, disability), psychosocial issues (e.g. coping, mood, and behaviours), and personal factors (e.g. working, caring for others, comorbidities) (3). UK research with >1,200 patients found 82% wanted support to manage pain and fatigue (4), yet patients report that fatigue is often not addressed in rheumatology consultations (5,6).

Cognitive-behavioural therapy (CBT) is one of the most helpful types of support for IA-related fatigue. Previous systematic reviews provide evidence that self-management courses which utilise CBT to increase self-efficacy (beliefs in the ability to carry out self-management behaviours) are more effective than interventions delivering information alone (7–9).

A team from psychology, nursing and occupational therapy designed a brief, low-intensity, intervention to address the impact of fatigue on patients with inflammatory arthritis, to be delivered by trained rheumatology health professionals (RHPS), using a manual, over 2-4 sessions. The first two core sessions were designed to take place face-to-face and within two weeks of each other. Two additional optional sessions could take place face-to-face or remotely, within the subsequent
four weeks. It was tested in a feasibility study (Fatigue – Reducing its Effects through individualised support Episodes in Inflammatory Arthritis – FREE-IA) (10).

The intervention aims to reduce the impact of fatigue by encouraging patients to link thoughts, feelings and behaviours influencing their fatigue and their responses to it. Requiring ‘buy-in’ from both patients and RHPs, the intervention uses an ‘Ask, don’t tell’ approach, based on techniques of guided discovery and Socratic questioning (11). The aim is for patients and RHPs to collaborate and identify relevant lifestyle factors that could be affecting levels of fatigue. The intervention uses tools such as daily activity diaries to assess activity patterns and sets patient-centred goals focusing on changing behaviours. It was designed to be integrated into routine consultations (sessions lasting 20-30 minutes) and fits well with a stepped approach to care (12) offering a low resource intensive treatment option, upon which more intensive services could be added if required.

This paper reports on the findings of a qualitative process evaluation nested within FREE-IA, which played a vital role in understanding the acceptability of the intervention from the perspectives of two groups; patients who attended sessions; trained RHPs who delivered sessions. It also explored how contextual factors might affect implementation, both as a larger national research study, and into normal clinical practice. The aims were to i) understand the acceptability of the intervention, and ii) identify potential refinements to the intervention.

Methods

Recruitment procedures
Six weeks after the first session, the study coordinator phoned patients to collect their fatigue score. During this call, patients were asked if they would like to take part in an optional telephone interview to discuss their views and experiences. If they agreed, a consent form and information sheet were posted to the patient, and contact details forwarded to the process evaluation research fellow (AB).

RHPs were recruited via their local principal investigator, and were provided with information sheets which explained that they would be invited to take part in an interview. Consenting patients and respective RHPs provided written informed consent by completing the consent form and returning a copy to the study team prior to interview.

Data Collection and Analysis
Two distinct qualitative data sets were collected from:
1. Patients who participated in FREE-IA sessions
2. RHPs who undertook FREE-IA training and delivery

Data were collected via one-to-one interviews by telephone. Interview questions were developed with collaborators and patient partners (Supplementary Data S1, available at Rheumatology Advances in Practice online). Patients were asked about the content and acceptability of the intervention. RHPs were asked about training and potential for integrating the intervention into clinical practice. Interviews were audio-recorded, transcribed verbatim and anonymised.

An inductive thematic analysis approach (13) was adopted to identify and analyse patterns, without the constraints of fitting data to a pre-determined theory. The process evaluation research fellow analysed the transcripts independently; including familiarisation of the data by reading the transcripts, initial labelling of early codes to describe small chunks of data that related to the research topic, then starting to search for patterns by grouping together clusters of related codes into initial themes (generally, broader and more abstract than the codes). The study PI contributed to this iterative process by looking at a subset of data to explore what common concepts they saw in the data and how these might be labelled. Both team members then worked together reviewing the themes and sub-themes, re-grouping them so that each theme (and related sub-themes) was representative of the data. The study coordinator and patient research partner also reviewed and commented on the themes. The final analysis was agreed in a meeting with the four team members. NVivo was used to organise the data sets.

Sample
The patient sample was recruited purposively to capture a diverse range of patients, including sex, age range, number of sessions attended, and from across all sites.
All 12 RHPs who took part in FREE-IA intervention training were approached to take part.

Results
Twenty-two patients took part in an interview. Demographics of the patient sample are presented in table 1. Eight RHPs agreed to be interviewed, and another 3 RHPs provided information via email. Interviews took place between March 2019 and May 2020.
Findings are presented as two distinct sets: 1) patient interviews, 2) RHP interviews.

(INsert Table 1 Here)
Patient Interviews

Four themes capture the views and experiences of the patients, and are evidenced using data excerpts. Data were fully anonymized following transcription, and ID codes used.

Theme 1: Collaborative, non-judgemental consultations

Patients reported developing positive therapeutic relationships with experienced and knowledgeable RHPs. They felt it was beneficial to have their fatigue validated, and to have time and space to reflect on its impact.

'I've had this for years and it's the first time anyone has particularly turned around and said, 'let's talk about fatigue'.'

(D461)

'Just that the fatigue is acknowledged… having a medical professional sit in front of you and say 'this is a thing… we understand it's a thing, we can't explain why it's a thing and we can't give you a tablet to fix it, but we understand it is a thing'.'

(D466)

They found the ‘Ask don’t tell’ approach helpful, and expressed their preference for a responsive, flexible approach to sessions, rather than a rigid, ‘protocolised’ approach.

‘Talking through my specific challenges with a bit of space, and a specialist to give me fresh ideas and not judge me… that one to one support and the time to talk about it, has been very, very welcome… very, very, helpful.’

(D468)

Theme 2: Relevant and useful, but not ground-breaking

Patients appreciated the range of topics covered, and valued the ability of RHPs to tailor content to individual priorities. Some had previously explored the topics covered, however, using visual illustration, for example, to communicate complex issues was very useful, and prompted new ways of looking at the issue.

‘It reinforced really what I should do, and what I needed to think about, and that was helpful… I mean I knew about trying to get proper sleep and relaxation. Trying to pace oneself, those kinds of things. It’s a case of understanding this, you don’t always remember to do it like that.’

(C343)
Being able to visualise the impact of lifestyle patterns on their fatigue using the daily activity diaries was helpful.

‘You don’t make any real connections, but when you see it… that was a very good visual clue, and I didn’t think that was going to be useful, but actually I found probably the most useful. It’s such a visual representation of what you are doing, or where you are slacking or crashing or whatever it may be.’

(D465)

‘That was the biggest wake up call for me… looking at the activity diary. Until you look at it - you could see that I didn’t have any pattern or any sort of resemblance to any normality at all. Everything was just chaos.’

(B221)

**Theme 3: Increased self-awareness, acceptance, and feelings of control**

Sessions increased patients’ awareness of lifestyle factors and patterns influencing their fatigue, which increased their sense of control and confidence to manage fatigue.

‘It just feels like I’ve got more control over fatigue… it’s given me permission and a licence to give myself that care, which I don’t think I was allowing myself before.’

(D468)

‘Some days… take you into nothing but red activity and today is heading in that direction. I will be ill if I allow that to happen, therefore it’s in my control. I can either do something about it and not feel so bad tomorrow, or ignore it and not be able to get up tomorrow.’

(B229)

Patients also highlighted how the sessions helped them to accept their fatigue, with this reflective process giving them ‘permission to relax’.

‘It’s not the be all and the end all now. I accept it is part of the condition, I accept that it might be there more prominent some days than others, or some weeks than others. And there’s no point worrying about it.’

(A103)
Theme 4: Degrees of openness to change
Sessions prompted some patients to engage in positive behaviour change, such as adapting sleep patterns, pacing, planning, and setting goals.

'It started me… paying a bit more attention to things like sleep and diet and lifestyle, but actually specifically thinking about how those could affect the fatigue… I'm sure the sessions helped with that'

(C344)

For others, the sessions ‘sowed the seeds’ and led to planning for future lifestyle changes.

'It's very easy to get into a rut and just do each day as it comes, and don’t even think about going forward or anything else… Having things to aim for… I have already booked a few things and doing things in the future.'

(D465)

However, some patients felt that any change in lifestyle would not affect their symptoms of fatigue.

‘I think my condition is governing my fatigue and I don't think there's anything that... I think it is what it is and I think for me the big thing is being more aware of it'.

(D461)

For some participants the broader effects of complex lifestyle situations meant it was difficult to consider or plan for change. Co-morbidities, work and family commitments, and lack of finances meant that engaging with positive lifestyle changes was impossible.

Rheumatology Health Professionals Interviews
Eight RHPs participated in interviews and three RHPs provided data via email. Three themes capture their views and experiences.

Theme 1: Engagement with the intervention
RHPs valued the face-to-face training delivered by the FREE-IA team and learning with peers, describing sessions as providing an opportunity to share ideas for learning.
‘You get much more engagement when you're face to face and you've got the different dynamics going on in the group... we would discuss the course together and different opinions... I thought it was really good.’ (ATTM1)

Some RHPs felt they would have benefited from ‘refresher’ training, when starting the sessions was delayed for local logistical reasons.

‘We all came out all guns blazing (following training), and then... it was a long time before we were able to get on the ground and see people. You kept re-reading the book, but I think it would have been probably better from my idea to have a refresher.’

(ETTM1)

For RHPs with extensive experience of providing fatigue support, the low level of treatment intensity and manualised approach limited the intervention’s usefulness. This led to a lower level of engagement and satisfaction compared to RHPs who had fewer resources to use with patients. Conversely, those with less experience of providing fatigue support prior to the study, reported gaining confidence as they delivered more sessions.

‘As I've been doing the sessions, the more confident I've got, part of it is knowing the people, but also knowing the material as well. I've really enjoyed it, because you can see how much a patient is getting out of it.’

(CTTM1)

‘Yes, 'ask, don't tell' - very, very difficult. Because I mean by nurses... by definition we advise our patients on theoretically what we think is best for them... it was quite hard to let go. That was very new... I think familiarity... the more I did it, the easier it became.’

(ETTM1)

Theme 2: Managing the intervention as a research study and clinical service

Sessions were often carried out outside of usual clinics, or at the end of a clinic so more time could be allocated if needed. RHPs expressed concern about fitting sessions into clinic appointments as a number of sessions lasted longer than the 20-30 minutes suggested length. Sessions ranged from 10 to 120 minutes, with an average (median) of 40 minutes.

‘If we were to focus on fatigue alone, no it wouldn't (work)... if it’s like a five-minute discussion on fatigue and how to manage it, then that’s fine... but anything longer than that... we wouldn’t fit it in.’
It was a challenge to offer patients a follow-up session within the desired two-week time frame, because of long waiting times and a high demand for available clinic appointments.

‘That was quite difficult because of the waiting list I have. Getting them in the first time was alright, but getting them in for the second appointment within a fortnight was quite difficult.’

Some RHPs described integrating the intervention approach and materials into their routine interactions with patients.

‘I have already taken advice from the manual and repeated it to patients in clinic. Snippets of useful information is a quick and easy way of helping patients when I am more pressed for time in a ‘normal’ clinic setting.’

**Theme 3: Collaborating with patients to address fatigue**

RHPs reported that patients were willing to try the tools and strategies during the sessions. Some RHPs followed the manual in a linear way, whilst others adapted content and used it more flexibly.

‘Obviously the activity diaries… I think they look at it, not realising the actual impact it has, once they’ve done it… they don’t realise until they do it.’

RHPs also reflected on those patients who did not engage, expressing that some might require a higher intensity approach and level of support.

‘Most of the ones who contributed to the study are proactive, and want to change, and they are willing to make changes. And then you have got other patients… who think that we can fix them by giving them a tablet, and we can’t. And they put up obstacles about everything you say… but I understand it’s hard…’

**Discussion**

**Acceptability**

A key finding within this study was the value of the collaborative, ‘ask, don’t tell’ approach adopted in sessions. Having space and time to discuss the impact of fatigue, and having it validated by a
healthcare professional was empowering. Patients and RHPs described how this approach enabled them to develop positive therapeutic relationships. Some RHPs found using the approach challenging, and this is where more training or experience of the intervention could have strengthened skills and confidence levels of the RHPs.

These findings align with previous literature which highlight the importance of shared decision making and collaborative working relationships (14). They strengthen the argument that collaborative, non-didactic consultations are able to foster increased self-efficacy, acceptance of fatigue, confidence in self-management, and feelings of control (14–16).

Patients and RHPs highlighted the value of particular tools and approaches, such as using the daily diaries to visualise lifestyle patterns. It is important to recognise elements of the intervention which might be more easily incorporated than others. Adapting the daily diary tool for use in everyday clinics could be explored in future research.

RHPs became more confident about the (often new to them) intervention approach and content as they delivered more sessions. These findings support earlier fatigue studies (17) and literature reporting a positive relationship between health professional self-efficacy and patient outcomes (18), highlighting the importance that a positive training experience and on-going support might have on health professional self-efficacy, and in turn patient outcomes.

**Refinements**

Patients valued working with a health professional who was familiar to them. RHPs were able to deliver the sessions, however, reported barriers to implementing the intervention into normal practice (in its current format) due to short clinic appointment slots, and the inability to carry out session 2 within two weeks. Some RHPs had adopted certain tools and topics, utilising them in everyday clinic appointments. This is an important finding, and highlights the possibility of adapting intervention content to make it more acceptable, and exploring how it could be better incorporated into a clinical setting.

For some participants the broader determinants of health impacting levels of fatigue were complex and multi-dimensional, and factors such as disease activity meant it simply wasn’t the right time for change. These findings highlight that a low intensity intervention will not be adequate for all patients experiencing symptoms of fatigue, but recognising that it has a place within a ‘stepped approach to care’ (12) being beneficial to a proportion of patients, but not an option for all.
Strengths
This study was able to uncover the experiences and attitudes about the sessions from both the patient and RHP perspective. It demonstrates sensitivity to context, and the wider determinants affecting fatigue, as well as highlighting the importance of the collaborative approach of the sessions. The methods adopted were able to un-pick the workings and nature of the sessions, including issues affecting approach, content, and delivery.

The sample was recruited from across all five NHS sites, and included participants who had attended between 1-4 sessions to gain insight into their reasons for opting to take part in more or less of the intervention. Recruitment occurred throughout the course of the study, enabling the sample to include patients who had sessions with RHPs with differing levels of experience of delivery. Two patient research partners were involved in the design of the study, this included feedback on patient information sheets and interview questions.

Limitations
The sample size, whilst relatively small at 22, was close to half of the total number of 46 patients who attended sessions, however, ethnic minority communities were underrepresented in the sample. We also collected no data on patient’s health literacy levels, known to affect self-management strategies in rheumatology (19). It is acknowledged that the findings might not reflect those of the wider population of patients with inflammatory arthritis who experience fatigue. It is possible that patients who consented to take part in an interview had a more positive experience of the sessions, however, interviews did take place with patients who attended for just one session, all the way through to those who attended all four sessions.

Next Steps
A sensible next step is to explore options for alternative modes of intervention delivery, and importantly how the ‘essence’ of the sessions, including the approach and tools, might be best translated. The move to online consultations since the COVID-19 pandemic in 2020 opens up the opportunity for more patients to engage with RHPs, but also presents challenges in terms of accessing intervention resources and working collaboratively. Digitalised content could make it easier for RHPs to provide guidance and copies of the diaries prior to the first session, so that lifestyle patterns can be explored together in the initial session.

Arguably, online working shows potential for how it might be possible to integrate such sessions into clinical appointments. It would be of value to further explore this with RHPs post-COVID, as well as observing what the ‘new normal’ looks like for different rheumatology clinics nationally.
Given the findings of the importance and value of the collaborative nature of the sessions, future research should explore if and how this approach translates into the digital consultation, and if it is affected in any way, from both the patient and RHP perspective. Future research will focus on adopting new ways of integrating sessions and content into potentially digital consultations, and developing content that can be used in a range of contexts and formats.

**Conclusion**

This study reports on the acceptability of a brief, cognitive-behavioural, one-to-one intervention to reduce fatigue impact within the NHS. The study presents novel key issues regarding the usefulness for this new intervention and demonstrates the potential for this intervention to benefit patients. Collaborative, positive, therapeutic relationships were able to be established between patients and RHPs, within a short period of time, and patients described feeling empowered, more in control and confident to address lifestyle patterns and consider positive behaviour change to improve self-management of their fatigue.

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References


Table 1 – Patient Demographics

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