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Original article

Remotely delivered cognitive-behavioural and personalized exercise interventions to lessen the impact of fatigue: a qualitative evaluation

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Abstract

Objectives. Fatigue can be a disabling symptom of inflammatory rheumatic diseases. LIFT (Lessening the Impact of Fatigue in inflammatory rheumatic diseases: a randomized Trial) is a randomized trial of remotely delivered cognitive-behavioural approach or personalized exercise programme interventions, compared with usual care. The aim of this nested qualitative study was to evaluate participants' experiences of taking part in the intervention, including their ideas about future service delivery.

Methods. Semi-structured telephone interviews were conducted with a subgroup of LIFT participants to discuss their views and experiences of the interventions.

Results. Forty-three participants (30 women) from six sites who had participated in the cognitive-behavioural approach ($n = 22$) or personalized exercise programme ($n = 21$) interventions took part. Five themes were identified in the thematic analysis. In the theme 'not a miracle cure, but a way to better manage fatigue', LIFT could not cure fatigue; however, most felt better able to manage after participating. Participants valued 'building a therapeutic relationship' with the same therapist throughout the intervention. In 'structure, self-monitoring and being accountable', participants liked the inclusion of goal-setting techniques and were motivated by reporting back to the therapist.

After taking part in the interventions, participants felt 'better equipped to cope with fatigue'; more confident and empowered. Lastly, participants shared ideas for 'a tailored programme delivered remotely', including follow-up sessions, video calling, and group-based sessions for social support.

Conclusion. Many participants engaged with the LIFT interventions and reported benefits of taking part. This suggests an important future role for the remote delivery of fatigue self-management.

Lay Summary

What does this research mean for patients?

Fatigue can be a disabling symptom in inflammatory rheumatic diseases (IRDs). The LIFT study (Lessening the Impact of Fatigue in inflammatory rheumatic diseases: a randomized Trial) looked at different interventions; a cognitive-behavioural approach (CBA), a personalized exercise programme (PEP)

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CLINICAL SCIENCE

or usual care. CBA sessions addressed unhelpful thoughts and feelings. The PEP sessions supported people with IRDs to increase their exercise levels gradually. People with IRDs were randomly selected to take part in seven sessions of CBA, seven sessions of PEP or usual care. All sessions except the first PEP session were delivered remotely by telephone. The aim of this study was to explore people's experiences of taking part. Forty-three people with IRDs (30 women and 13 men) were interviewed from six UK locations. Twenty-two took part in the CBA sessions, and 21 took part in PEP. People with IRDs who took part in LIFT told us about a range of benefits. These included feeling less fatigue and more confidence. Those in PEP told us they felt stronger. People with IRDs shared that they liked being able to talk about their fatigue with a supportive therapist. These are encouraging results for remotely delivered research to support people with fatigue.

Key words: patient perspectives, qualitative, fatigue, rheumatic diseases, exercise, cognitive-behavioural approaches

Key Messages

- Patients reported benefits of LIFT interventions, including reduced fatigue, increased strength (for those in the personalized exercise programme) and improved confidence.
- Many patients valued being able to examine their fatigue in a supportive patient–therapist relationship.
- These findings highlight the advantages of clinical implementation of a remotely delivered intervention to address fatigue.

Introduction

Fatigue can be a common, persistent and disabling symptom in inflammatory rheumatic diseases (IRDs), including RA, PsA, SLE, AS, axial spondylarthritis (AxSpA) and primary SS (pSS). Patients have described the extensive social, emotional, cognitive and physical impact of the symptom on their daily lives [1]. Aside from pain, patients report that fatigue is the most difficult symptom to manage [2–4]. In RA, between 42 and 80% of patients experience significant fatigue. In a study of patients with AS, 66% of those surveyed reported severe fatigue [5]. For those with SLE, ∼86–95% of patients with SLE experienced significant fatigue [5–8]. Patients with inflammatory arthritis have described fatigue as 'overwhelming' and different from everyday tiredness, which could make them feel drained. Many struggled with everyday activities, having to reduce their actions to a minimum in order to carry on with daily activities, work and leisure [4]. Likewise, those with FM also described overwhelming tiredness, feelings of weakness or heaviness, difficulties in doing the things they needed to do, and having to do things more slowly because of fatigue or tiredness [9]. It is clear that for patients with IRDs, fatigue has a substantial impact on their day-to-day lives [5–9].

In the UK, >80% of patients with IRD have indicated that they would like more support from health professionals to manage the impact of pain and fatigue on their lives [10]. Although rheumatology health professionals are aware of the impact of fatigue, many are unsure how best to support patients [11]. This could, in part, be attributable to a limited understanding around the causality and mechanisms of fatigue in IRD. However, conceptual models recognize fatigue as multifaceted, with contributory factors that are likely to vary within and between individuals and change over time [12, 13]. Evidence supports interactions between disease activity and treatment processes (such as inflammation and medications), physical activity, psychological factors (including emotions, cognitions and behaviour), sleep problems, obesity and social factors (including work/caring responsibilities and financial resources). Rather than linear interactions, these relationships are likely to be complex, dynamic and reciprocal, with individuals' experiences of fatigue being influenced by their unique factors. This suggests a role for interventions that acknowledge these factors and tailor approaches to the individual. In rheumatology, most of the evidence about fatigue management has focused on RA. This includes a systematic review of non-pharmacological interventions, which reported small to moderate effects for physical activity and psychosocial approaches [14]. Given that there might be a number of shared similarities in the patterns of behaviour that maintain fatigue across chronic inflammatory rheumatic diseases, the trial was designed to be a broader intervention, applicable across many chronic painful conditions [15].

Lessening the Impact of Fatigue in inflammatory rheumatic diseases: a randomized Trial (LIFT) is a multicentre three-arm randomized trial of remotely delivered cognitive-behavioural approach (CBA) or personalized exercise programme (PEP) interventions in addition to usual care, compared with usual care alone [15]. Using a computer-generated sequence, participants were allocated to one of the two treatments (CBA or PEP) or

usual care alone [15]. The CBA and PEP interventions were adapted by the authors from previous cognitive-behavioural and physical activity interventions to manage fatigue [16, 17] to ensure that they were applicable to a variety of IRDs and appropriate for remote delivery. The CBA intervention addressed unhelpful cognitive and behavioural patterns, such as avoidance of activity or boom–bust cycles of overexertion and enforced rest (crash), by encouraging participants to consider the cognitions and emotions associated with these behavioural patterns. In the PEP intervention, individual programmes to increase participants' exercise levels gradually were designed, based on their symptoms. The aim was to modify participants' perceptions of effort and improve their exercise tolerance. Participants in PEP also tracked their activity using fitness-monitoring devices (heart rate monitors and pedometers). The interventions comprised seven sessions, each lasting $\leq$45 min, spread over 14 weeks and with a booster session at 22 weeks. They were delivered by health professionals (rheumatology nurses, occupational therapists and specialist physiotherapists) via telephone, except for the first session of PEP, which was delivered face to face. The aim of this nested qualitative study was to evaluate participants' experiences of taking part in the intervention, including their ideas about future service delivery.

Methods

The study was approved by the Wales Research Ethics Committee Number 7 (reference: 17/WA/0065). A subgroup of LIFT participants who had been in the CBA or PEP arm of the trial were invited to take part in a semi-structured telephone interview after they had completed their final set of outcomes. Qualitative methods were chosen to explore participants' views and experiences of the LIFT intervention. Data were collected in semi-structured interviews informed by a topic guide devised, piloted and refined by the authors of the present study. The topic guide included participants' reasons for joining the study, their views on the intervention and its impact on their fatigue (Table 1).

Sampling and recruitment

Potential participants were sampled from six National Health Service hospital sites taking part in the LIFT study across the Northeast of England and Scotland. Potential participants were eligible if they had been allocated to an intervention arm of the trial and they had completed their week 56 assessment visit [15]. A maximum variation sampling strategy was used to target LIFT participants with a range of age, sex and IRD diagnoses [18]. To achieve the maximum variation sampling strategy, a minimum of 40 interviews was calculated as being required, in order to explore a variety of experiences of intervention training and delivery across a diverse sample of participants and across two interventions [15]. All participants provided audio-recorded verbal informed consent for the qualitative component. Participant codes have been used throughout to maintain anonymity.

Table 1 Semi-structured interview topic guide

Overarching topic	Areas to explore
Fatigue	Nature and impact of fatigue before the intervention
	Reasons for taking part in LIFT
	Expectations of the intervention
Content and delivery	How much of the intervention was completed and why?
	Usefulness, memorable aspects, most helpful and least helpful elements
	Views on intervention delivery and duration
Acceptability of the intervention	Mood over the course of the intervention
	Challenges and benefits experienced
	Ideas for altering the intervention
Impact on fatigue and daily life	Changes to fatigue since starting the intervention (including physical, psychological and social wellbeing)

LIFT: Lessening the Impact of Fatigue in inflammatory rheumatic diseases: a randomized Trial.

Data collection and analysis

Interviews were conducted between March 2019 and September 2020 and lasted for 20–47 min (average 26 min). Before the start of their interview, participants were reminded that the telephone call was being recorded, and consent was audio-recorded. Data were collected by two female research associates (C.A. and S.B.), both with prior experience of conducting semi-structured interviews via telephone. C.A. and S.B. were not involved in the design or delivery of the CBA and PEP interventions. A digital audio-recorder or speakerphone and in-line recording adapter was used to record the telephone interviews. The audio recordings were transcribed by a professional transcription service, checked for accuracy by C.A. or S.B., and anonymized.

Data were analysed using an inductive thematic analysis from a realist, semantic perspective, guided by the six-step process outlined by Braun & Clarke [19]. Inductive thematic analysis was chosen owing to its suitability for data-driven analysis comparing patterns across a dataset [20]. The lead author (S.B.) imported the transcripts into NVivo 12 (QSR International, Melbourne, Victoria, Australia) qualitative data evaluation software to manage the data. All 43 transcripts were read and re-read, before being coded for sections of text that were relevant to the aim of the research. Related codes were grouped together to form subthemes, whereas others were promoted to overarching themes within the data [19]. Co-authors (E.D., C.A., L.P. and A.W.) with significant qualitative research

experience reviewed a sub-set of transcripts independently. Theme labels and content were discussed as a group, and the final analysis was agreed by these five research team members (S.B., E.D., C.A., L.P. and A.W.).

Results

A total of 43 participants were interviewed, from a possible 103 CBA and 90 PEP participants who had completed the trial and engaged with follow-up (week 56). The sample comprised 30 women and 13 men from the CBA arm ($n = 22$, 21.35% of the sample) and the PEP ($n = 21$, 23.3% of the sample). Participants were purposively sampled to give variation in relationship to age, sex, diagnosis and intervention allocation. They were aged <50 (10; 23%), 50–65 (19; 44%) or >65 years (14; 32%). See Table 2 for participant characteristics. The authors identified five themes in the data (Table 3).

The first identified theme, 'not a miracle cure but a way to better manage fatigue', explored participants' fatigue before the programme. The subthemes 'not knowing what was wrong' and 'not recognized by

Table 2 Demographic characteristics of the study sample ($n = 43$)

Age, range, years	Sex	Diagnosis	Site	Intervention arm	Therapist code
>65	M	RA	1	CBA	01
>65	F	RA	1	CBA	02
>65	F	pSS	1	CBA	03
>65	M	RA	1	CBA	04
50–65	M	RA	1	CBA	01
>65	F	RA	1	CBA	01
>65	F	RA	1	CBA	03
<50	M	AxSpA	1	CBA	04
50–65	F	SLE	1	CBA	03
50–65	F	RA	1	CBA	03
<50	M	PSA	1	CBA	04
50–65	M	RA	2	CBA	05
50–65	M	PSA	2	CBA	05
>65	F	PSA	2	CBA	05
>65	M	RA	2	CBA	06
50–65	M	RA	3	CBA	07
<50	F	SLE	3	CBA	08
50–65	F	RA	3	CBA	08
<50	F	SLE	4	CBA	09
50–65	F	SLE	4	CBA	09
<50	F	pSS	5	CBA	10
50–65	F	PSA	6	CBA	11
>65	F	RA	1	PEP	12
50–65	F	SLE	1	PEP	12
50–65	F	RA	1	PEP	12
<50	F	SLE	1	PEP	12
50–65	F	SLE	1	PEP	12
50–65	M	AxSpA	1	PEP	13
<50	M	AxSpA	1	PEP	12
<50	F	RA	1	PEP	14
<50	F	RA	1	PEP	15
>65	M	PSA	1	PEP	14
50–65	F	SLE	2	PEP	16
50–65	F	RA	3	PEP	17
50–65	M	AxSpA	3	PEP	17
>65	F	RA	3	PEP	18
>65	F	SLE	4	PEP	19
50–65	F	PSA	4	PEP	19
50–65	F	pSS	5	PEP	20
50–65	F	pSS	5	PEP	20
<50	F	SLE	5	PEP	20
>65	F	FM	5	PEP	20
>65	F	RA	6	PEP	21

AxSpA: axial spondyloarthritis; CBA: cognitive behavioural approach; F: female; M: male; PEP: personalized exercise programme; pSS: primary SS.

Table 3 Themes, subthemes and supporting quotes from the thematic analysis

Theme	Subtheme	Supporting quotes
Not a miracle cure, but a way to manage fatigue	Not knowing what was wrong	I think the worst thing was not knowing what was wrong but knowing that I had something wrong [CBA 001]
		I don't think I really recognized it as being part of the rheumatoid [PEP 43]
	Not recognized by rheumatology professionals	Fatigue . . . there seemed to be a non-recognition on the part of rheumatology that this was central to my condition [CBA 007]
		I don't think . . . fatigue . . . is very well understood [CBA 016]
	Keen to try	The GP wasn't helpful, so I had to find my own way, so when this came along I thought, 'Right, I'll try. . . I'll do anything' [PEP 041]
		I knew it wasn't a miracle cure, not like it would suddenly, like, take the condition away. I just felt [LIFT] was well, just another tool in my box, sort of thing, that I could pull out when I needed it, and that's what it transpired to be [CBA 004]
		I was quite happy to take part in it, you know, to try anything to get a benefit and see if I could get a better quality of life . . . because I've tried everything else [PEP 034]
Building a therapeutic relationship	Therapists who understood IRD fatigue	I liked the physiotherapist that I got allocated, she was really good, and because she has a family member that's got RA she could relate more [PEP 031]
		I wouldn't have liked to join a gym with some super trainer there who has no idea about medical conditions [PEP 026]
		Because she was an OT and [part of the] team that work with [RA] she understood [CBA 004]
	Continuity of care	They remembered things from your last visit and just different things, and I think it was due to the continuity of the same face and the same voice and stuff like that makes a difference [CBA 008]
		It was really good having that support, on the end of the phone okay, knowing that someone was there interested in what I'd managed to achieve that week or that fortnight [PEP 029]
Structure, self-monitoring and being accountable	The value of follow-up	. . .because you know that person is going to be 'phoning you and asking you. So, you think, 'Oh, well, I'd better make an effort. Better make sure I've made an effort this week', and I think that's quite a good thing [PEP 036]
		I think if I'd been told just to get on with it and I knew that nobody was going to be 'phoning and checking up on me then I probably would've . . . I'd quite easily miss out days and here and there [PEP 031]
	Setting achievable goals	We agreed them [goals] together on the basis of where I live and what seemed suitable [PEP 030]
		[The LIFT therapist] said, 'Don't get upset or frustrated if you don't achieve the things that you wanted to achieve, because you're doing okay' [CBA 005]

(continued)

Table 3 Continued

Theme	Subtheme	Supporting quotes
Better equipped to cope with fatigue	Greater understanding of the symptom	I keep a diary each day now, and I find that brilliant, to be honest. It helps you understand why I did feel the way I did that day [CBA 022]
		I started keeping a fatigue diary and I still do that now; I've kept it going. One of the things that I noticed very, very quickly was a pattern that I hadn't really thought of, and having noticed the pattern I was then able to alter my working, my working regime to try and avoid the boom and bust sort of idea [CBA 006]
	Feeling more positive in the face of fatigue	What is different is that I have more enthusiasm about doing things.. . . It's given me my courage back, I think [PEP 035]
		I think it's given me a lot of confidence, and the fatigue's a lot better [PEP 037]
		Yes, on the whole, I feel more positive about coping with fatigue [CBA 005]
	Not as effective if already active	I was walking daily anyway, and I still am walking daily, at least one and a half kilometres, maybe two during the week, and much higher at the weekend [PEP 026]
		[The LIFT Trial's] overall impact was limited because it did not show me anything that I was unaware of beforehand [CBA 007]
A tailored programme delivered remotely	Benefits of telephone delivery	I live out-with the city centre in a sort of rural area . . . just even getting myself organized to go to appointments and things like that, I found really hard, and it just added to the fatigue [CBA 004]
		I found it quite beneficial because it meant I didn't have to go travelling up to see them [PEP 027]
	On-going support	It can't be continual, on-going, but I think if you had somebody . . . almost like checking up on you, because self-motivation's okay, but after a while, you know, life just gets in the way [PEP 031]
		Maybe another couple of sessions further down the line checking back in, if you'd fallen off the wagon as it were, or just how are you doing kind of thing, would have been quite good [CBA 021]
		I still have a sort of hankering of meeting with other people to see how they were coping because sometimes one feels quite isolated [CBA 005]

CBA: cognitive behavioural approach; GP: general practitioner; IRD: inflammatory rheumatic disease; LIFT: Lessening the Impact of Fatigue in inflammatory rheumatic diseases: a randomized Trial; OT: occupational therapist; PEP: personalized exercise programme.

rheumatology professionals' addressed the disabling fatigue experienced by men and women, and the lack of support they experienced in their care. Many were 'keen to try' the LIFT programme and, although recognizing that the therapies would not cure their fatigue, many described being 'better able to cope with fatigue' (theme 4), a 'greater understanding of the symptom' and feeling more confident in their abilities after participating. 'Building a therapeutic relationship' explored the partnership between the LIFT therapist and their participant. Participants also described in theme 3 how 'setting achievable goals' and having their activity regularly followed up gave them structure and accountability. Lastly, benefits of the remote delivery of the programme are explored.

Not a miracle cure, but a way to better manage fatigue

Not knowing what was wrong

Participants were living with disabling fatigue, with substantial impact on their work and social lives.

Participants spoke of losing their identity, their reason to get out of bed, and feeling 'trapped' by fatigue. Before taking part in LIFT, some participants had not made the connection between their IRD and their fatigue. Not knowing about fatigue could be very worrying and was described as one of the most distressing elements of their experience. Men, particularly, worried about how their fatigue affected their ability to work, and the need for extra time off.

Not recognized by rheumatology professionals

Participants reported that health professionals often struggled to recognize and discuss the association between IRD and fatigue. Other participants indicated a perceived lack of interest or understanding from their doctors about the impact of IRD-related fatigue. As a result, some participants felt that there was a lack of appreciation of the significant impact of fatigue on their lives, with little support available.

Keen to try

Participants recognized that LIFT could not offer a miracle cure, but the majority felt better able to cope with their fatigue after taking part. Participants were motivated to understand the associations between their IRD and fatigue, to gain more information and support with management and to help themselves to live well. Many had already tried a range of self-management strategies and were keen to see if LIFT would make a difference.

Building a therapeutic relationship

Therapists who understood IRD fatigue

Participants in the CBA and PEP arms reported feeling validated by LIFT therapists who acknowledged and understood the impact of IRD fatigue. Those in the PEP arm described how having their exercise directed by a physiotherapist with comprehensive knowledge of IRD and fatigue was reassuring, and they felt encouraged to increase their activity levels safely. Participants in the CBA arm also reported that it was reassuring to talk to LIFT therapists who provided fatigue support and advice in keeping with their individual goals.

Continuity of care

Participants valued interacting with the same therapist throughout the intervention. Many reported that the rapport they were able to build at the start of the intervention made it easier to share more personal things later. Participants in both arms cited the quality of their relationship with their therapists and described feeling encouraged and supported to push themselves to do more. Having a good relationship with their LIFT therapist gave participants the space confidently to tackle how they felt about their fatigue in a supportive environment.

Structure, self-monitoring and being accountable

The value of follow-up

Many participants liked the structured format of the interventions, and most were happy with the seven sessions. The inclusion of techniques such as goal setting were described as motivating and helpful because they included self-monitoring and being accountable to the therapist. Participants in the CBA arm described how keeping an activity diary enabled them to see the cause and effect of their boom–bust cycles of activity and to see new connections between their overexertion and fatigue crashes. Filling out activity diaries and charts enabled those in the PEP arm to see their progress each week. Knowing that they would be 'checked up on' and accountable to a therapist via weekly telephone calls helped PEP participants continue to try to achieve their goals. Correspondingly, some described how it was sometimes difficult to stay motivated when the seven LIFT sessions had finished.

Setting achievable goals

Individual goal setting led by participants was acknowledged as a helpful part of the interventions, although learning how to set achievable goals could be challenging. Many were keen to set goals, but were cautioned by their therapist in both the CBA and PEP arms to try not to do too much at once. Some participants described feelings of guilt when they had not been able to meet the weekly goals that they had set for themselves. However, this response was often used as an incentive to set more realistic goals and objectives.

Better equipped to cope with fatigue

Greater understanding of the symptom

Many participants described feeling more confident and empowered after the interventions, which they attributed to a better awareness of the drivers and maintaining factors contributing to their IRD-related fatigue. As a result, they felt much less isolated by their symptoms. Having a better understanding of their fatigue empowered participants to 'take back control' from their fatigue, rather than feeling passive.

Feeling more positive in the face of fatigue

Some participants reported that the changes after taking part in the interventions were as much psychological as physical, highlighting a new attitude towards fatigue self-management. Positive benefits included being more motivated to socialize and to exercise and being able to pace activity better. Many were so pleased at their physical progress that they were continuing to exercise after the programme had finished. Some in the PEP arm reported enhanced muscle tone and physical stamina, which almost all reported as making them feel 'stronger', helping with physical mobility and improving joint pain. Some CBA participants had carried elements of the intervention into their everyday activities; using the

activity diaries to track fatigue levels over the day and modifying their actions to avoid boom–bust cycles of activity.

Not as effective if already active

Participants in the PEP arm who reported high physical activity levels before LIFT reported less benefit from the intervention. This might be attributable to the programme being targeted to the needs of patients with a much lower baseline of exercise and physical activity. There were some participants in both CBA and PEP arms who reported being reluctant to keep an activity diary, set written goals or complete questionnaires because they felt that there was nothing to gain from these activities and tasks and that they would not provide any new information, insights or help.

A tailored programme delivered remotely

Benefits of telephone delivery

Participants found telephone delivery an acceptable way to interact with their therapist. Many described the telephone calls as convenient, with less impact on their fatigue compared with travelling to meet in person. Several in the CBA arm reported that they felt more able to be open, relaxed and honest on the telephone compared with in person.

On-going support

Participants had a range of suggestions for delivery of LIFT in clinical practice. This included further follow-up sessions 6 and 12 months after the intervention, to prevent a possible 'slide' back into less active behaviours. With the recent changes in social interaction because of the current coronavirus disease 2019 (COVID-19) pandemic, including reliance on video calling platforms, many were keen to see this as an option to check in with their therapist. Participants cited seeing facial expressions as further strengthening inter-personal bonds. In addition, a minority were keen to see LIFT broadened to group-based sessions. The hope was that by meeting others with IRD fatigue, participants would receive social support, ideas and encouragement.

Discussion

These findings highlight the significant potential benefits of remotely delivered CBA and PEP interventions. This includes the value to patients of validating their experiences and providing information, advice and reassurance about fatigue from a rheumatology perspective. The lack of recognition and acknowledgement of fatigue by health-care professionals before the interventions had left some participants struggling and unsure of the best way to cope. This is in line with research showing that patients with RA felt dismissed when trying to discuss fatigue with their general practitioner and perceived health professionals as reluctant to provide support [4]. Our study findings also reinforce the importance of the therapeutic relationship, rapport building and therapist continuity, which have been shown to improve outcomes for patients in several long-term musculoskeletal conditions, including low back pain [21, 22] and OA knee pain [23]. It also shows that the therapist–patient alliance can work well via telephone. This is interesting, because telehealth is becoming commonplace in rheumatology [24]. In some clinical areas, such as psychological therapy, there is evidence that therapists and patients have reservations about telephone delivery, despite comparable clinical outcomes [25]. These concerns centre around the quality of the therapeutic relationship and the ability to exercise professional skill and judgement in the absence of visual cues. One possible explanation for the positive experiences of participants in the present study is the long-term nature of IRD. Participants were used to coming into hospital as part of managing their health. Taking part in the interventions was an opportunity to save time and energy, while still accessing specialist rheumatology care.

Techniques such as goal setting, self-monitoring and accountability were described by participants in our study as motivating and helpful. Similar results have been seen in a supervised exercise programme for type 2 diabetes, in which participants appreciated the encouragement, monitoring and accountability provided by programme staff and were keen to push themselves [26]. Although our findings showed support for the use of key behavioural techniques to enhance participants' self-efficacy, they also highlight the risk of patients failing to sustain positive behaviours when they are no longer reporting to others. This sense of on-going support was mentioned by participants interested in group work and sharing experiences with other patients. A buddying system could help to transition participants from the structured environment of the LIFT study to real-world exercise routines post-intervention [27, 28]. Another model of interest is the co-production of peer support groups after pain management programmes. These have been shown to be low-cost, provide helpful social intervention, improve self-management skills and lead to some reductions in usage of health services [29].

Those in the PEP arm reported enhanced muscle tone and physical stamina after the intervention, which made them feel 'stronger', and helped with physical mobility and joint pain. Comparably, a recent randomized controlled trial examining 3-month personalized exercise programmes for patients with RA found that participants had increased grip strength, aerobic capacity and cognitive capacity and reduced fatigue scores on completion of the programme, compared with the control group [30]. The authors conclude that cardiovascular exercise has a significant positive impact on patients with RA [30].

Participants in the LIFT study were positive about the interventions being delivered via telephone, but they could see a potential role for the option of video platforms. Recent research has indicated that consultations using video calls in a musculoskeletal care setting were well received by the majority of patients [31]. The benefits include a reduction in waiting times, not needing to

travel (which can exacerbate fatigue) and savings to the patient in terms of travel costs [32]. Video consultation also enables visualization, making the explanation of tools, such as the colour-coded activity diaries, easier for participants to share.

Strengths and limitations

A strength of this study is the range of participants who took part in the telephone interviews, in relationship to sex, age, IRD, study site and therapist. A limitation of the study is that participants were only selected from those who reached the trial study endpoint at week 56. Although participants were invited if they had given the study team permission to be contacted before their withdrawal, none of those who had given permission responded to the invitation. Therefore, we do not have any insights from participants who did not complete the study. Our findings might give a more positive representation of CBA and PEP, compared with those who failed to complete the intervention. Future research could examine participants' reasons for non-completion of fatigue interventions.

Conclusion

This study found significant potential benefit of the LIFT interventions and the use of PEP and CBA to target fatigue in adults with IRDs. Many patients engaged with the LIFT interventions and reported several benefits of taking part, including increased strength (PEP), reduced fatigue, improved confidence and being able to examine their fatigue in a supportive patient–therapist relationship. Many were keen to continue the activity diaries and goal setting after completing the intervention, because these were described as an easy way to visualize energy expenditure over time. Most participants were happy with the remote delivery of the interventions and pleased to interact with therapists who understood their conditions and the impact of fatigue on their lives. These results suggest an important role for the remote delivery of fatigue self-management interventions, particularly as services respond and adapt to the current COVID-19 pandemic.

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Data availability statement

Anonymised individual patient data will be made available following any reasonable request made to the corresponding author, subject to a data sharing agreement and UK research governance regulations.

Supplementary data

Supplementary data are available at *Rheumatology Advances in Practice* online.

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*From biochemical assays, the clinical relevance of which is uncertain.
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Infections: Infections, including serious infections such as pneumonia and opportunistic infections e.g. tuberculosis (TB), oesophageal candidiasis, and cryptococcosis have been reported. Risk benefit should be assessed prior to initiating in patients with risk factors for infections (see SmPC). Patients should be closely monitored for the development of signs and symptoms of infections during and after filgotinib treatment. Treatment should be interrupted if the patient is not responding to antimicrobial therapy, until infection is controlled. There is a higher incidence of serious infections in the elderly aged 75 years and older, caution should be used when treating this population. Tuberculosis: Patients should be screened for TB before initiating filgotinib, and filgotinib should not be administered to patients with active TB. Viral reactivation: Cases of herpes virus reactivation (e.g., herpes zoster), were reported in clinical studies (see SmPC). If a patient develops herpes zoster, filgotinib treatment should be temporarily interrupted until the episode resolves. Screening for viral hepatitis and monitoring for reactivation should be performed. Malignancy: Immunomodulatory medicinal products may increase the risk of malignancies. Malignancies were observed in clinical studies (see SmPC). Fertility: In animal studies, decreased fertility, impaired spermatogenesis, and histopathological effects on male reproductive organs were observed (see SmPC). The potential effect of filgotinib on sperm production and male fertility in humans is currently unknown. Haematological abnormalities: Do not start therapy, or temporarily stop, if Absolute Neutrophil Count (ANC) <1 × 10^9 cells/L, ALC <0.5 × 10^9 cells/L or haemoglobin <8 g/dL. Temporarily stop therapy if these values are observed during routine patient management. Vaccinations: Use of live vaccines during, or immediately prior to, filgotinib treatment is not recommended. Lipids: Treatment with filgotinib was associated with dose dependent increases in lipid parameters, including total cholesterol, and high-density lipoprotein (HDL) levels, while low density lipoprotein (LDL) levels were slightly increased (see SmPC). Cardiovascular risk: Rheumatoid arthritis patients have an increased risk for cardiovascular disorders. Patients should have risk factors (e.g., hypertension, hyperlipidaemia) managed as part of usual standard of care. Venous thromboembolism: Events of deep venous thrombosis (DVT) and pulmonary embolism (PE) have been reported in patients receiving JAK inhibitors including filgotinib. Caution should be used in patients with risk factors for DVT/PE, such as older age, obesity, a medical history of DVT/PE, or patients undergoing surgery, and prolonged immobilisation. Lactose content: Contains lactose; patients with rare hereditary problems of galactose intolerance, total lactase deficiency or glucose-galactose malabsorption should not take filgotinib. **Pregnancy/Lactation:** Filgotinib is contraindicated in pregnancy. Filgotinib should not be used during breast-feeding. Women of childbearing potential must use effective contraception during and for at least 1 week after cessation of treatment. **Driving/Using machinery:** No or negligible influence, however dizziness has been reported. **Side effects:** See SmPC for full information. Common (≥1/100 to <1/10): nausea, upper respiratory tract infection, urinary tract infection and dizziness. Uncommon (≥1/1000 to <1/100): herpes zoster, pneumonia, neutropenia, hypercholesterolaemia and blood creatine phosphokinase increase. 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▽ Additional monitoring required

Adverse events should be reported.
For Great Britain and Northern Ireland, reporting forms and information can be found at yellowcard.mhra.gov.uk or via the Yellow Card app (download from the Apple App Store or Google Play Store).
Adverse events should also be reported to Galapagos via email to DrugSafety.UK.Ireland@glpg.com or 00800 7878 1345

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