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Fatigue in inflammatory arthritis

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Introduction

This paper on fatigue in inflammatory arthritis (IA) is informed by research evidence and clinical practice. The conditions covered include rheumatoid arthritis (RA), psoriatic arthritis (PsA), spondyloarthritis (axSpA) (including ankylosing spondylitis (AS)), systemic lupus erythematosus (SLE) and primary Sjogren syndrome (pSS). The authors professional backgrounds are physiotherapy (FC), psychology (ED), occupational therapy (KH) and nursing (JP). While we recognise that fatigue is a symptom that can affect people at all ages and with a range of musculoskeletal conditions, the focus in this paper is on adults with IA, SLE and pSS as these are our areas of expertise. We are interested in fatigue because it is common in IA and often described by those affected as their most problematic symptom.¹

Due to differences in definitions and measures, fatigue prevalence estimates vary from around 40% to over 80%.^{2,3} An international study of >6,000 people with IA found that one out of every two was severely fatigued, defined as scoring ≤ 35 on the SF-36 Vitality Scale.⁴ In RA, research has established that fatigue is present on most days for most people, with >70% reporting levels like those seen in Chronic Fatigue Syndrome, although the causes and the consequences may be distinct.^{5,6} A study based on two UK cohorts found that over 80% of people with RA had clinically relevant fatigue (Visual Analogue Scale (VAS) ≥ 20 mm) and over 50% had high levels of fatigue (VAS ≥ 50 mm).⁷ Research in AS estimates the figure to be 53% - 65%,^{8,9} while research in SLE has put the figure at 67% - 90%.¹⁰⁻¹² In a study with people with pSS, 86% rated fatigue as the most important symptom to address.¹³ In people with PsA, moderate fatigue has been estimated to affect 49.5% and severe fatigue in 28.7%.¹⁴ Recently, authors in Denmark conducted a cross sectional survey with 488 people with RA, PsA, and axSpA. Although the study population were a clinically stable group with low disease activity and few disease-related treatment changes, 61% reported that they were affected by fatigue.¹⁵ These high levels of fatigue can be chronic. A Dutch study using the fatigue subscale of the Checklist Individual Strength (CIS) concluded that 40% of people with RA experienced persistent severe fatigue over a one-year period, based on a validated cut-off score of ≥ 35 .^{16,17}

In this paper, we start by focusing on the perspective of people living with IA and fatigue, including the experiential nature of the symptom and its impact on realms of daily life. We then present current conceptual models of mechanisms and factors that may cause and maintain fatigue, both within and between individuals. Next, we address fatigue measurement and modes of assessment, which is an

integral aspect of management and evaluating support provision. This leads to a review of the research evidence for non-pharmacological interventions to reduce fatigue severity and impact. Finally, we consider implementation of this evidence and an inter-disciplinary perspective on fatigue management in clinical practice. This includes practical tools and techniques.

Living with fatigue

Qualitative studies have explored the experience of living with fatigue in people with IA. They perceive fatigue as an overwhelming problem which can have a greater impact on their lives than pain.¹⁸⁻²² Most of the research has focused on people with RA, and in 2019 these findings were brought together in a qualitative meta-synthesis²³ of published studies.^{20 24-28} The systematic interpretive analysis identified an overall theme of 'a vicious circle of an unpredictable symptom'. Four interconnected subthemes were: 'being alone with fatigue', 'time as a challenge', 'language as a tool for increased understanding', and 'strategies to manage fatigue'. People with RA reported that their fatigue is difficult to control, with considerable consequences for every aspect of their daily lives. They explain that their RA-related fatigue is unearned and different to the tiredness or exhaustion experienced prior to diagnosis. People describe how their fatigue is unpredictable and how it varies in severity, duration, frequency and intensity.

People with IA have described physical, cognitive, emotional and social experiences of fatigue.²⁸ The physical impact of fatigue can create a barrier to physical activity; with the body feeling heavy and unwell. Fatigue can also impact cognitive abilities, making it difficult to learn, focus, solve problems and engage with others. The emotional impact of fatigue has been experienced as frustration, hopelessness, fear, reduced motivation, lack of patience and exhaustion. Socially, fatigue can restrict people's ability to fulfil social roles in the family, in the wider social network, at work and in relation to leisure activities.

The impact of fatigue can lead to loneliness when people with the symptom find it hard to socialise. Often, they try not to show that they are fatigued when in company or they avoid social contact completely and try to manage on their own. Even in consultations with rheumatologists and health professionals, their fatigue is rarely addressed; consequently, people can feel left alone to cope with the challenge.²³ For many, it can be hard to ask for help and they do not wish to feel dependent on other people. Time becomes a challenge as managing their fatigue can mean that people need to take breaks during the day, with tasks often taking longer and requiring more effort than pre-diagnosis. People with RA-related fatigue feel that those without arthritis do not understand the tremendous

impact the invisible symptom has on their lives. As a result, they can be very conscious about the words they use to describe their fatigue when they talk to other people to help convey the full meaning and impact.²³

Living with fatigue has been less researched in people with other types of inflammatory arthritis, compared to RA. However, there are a few studies which have included the experiences of people with AS, PsA, and SLE.^{20 29 30} Descriptions of fatigue by people with AS are like those of people with RA, including feeling 'tired', 'exhausted', 'worn out' or 'wiped out', with fatigue leading to cognitive problems such as difficulty concentrating and being 'too tired to think'. Like people with RA, they describe variations in fatigue over the course of a day. Fatigue is often worse in the evening, but people can also wake up feeling fatigued.²⁰ People with AS identify various factors which influence their fatigue, such as older age, lack of sleep, low-mood, night-time pain, depression, lack of concentration, side effects from medication, work commitments and the unpredictability of the condition. People with PsA also experience 'unstoppable and far reaching fatigue' which is different from normal tiredness.³⁰ Their fatigue is linked to lack of motivation, loss of appetite and bodily pain.³⁰ People with SLE use similar words to describe their fatigue ('worn out', 'lack of energy', 'exhaustion' and 'not wanting to do anything') and they also find that the frequency and severity of their fatigue varies from day to day.²⁹ People with SLE describe the physical consequence of fatigue as 'feeling weak' while the emotional impact concern mood swings, irritability, helplessness, anger, anxiety, tearfulness and feeling miserable. In their view, fatigue is associated with depression and cognitive difficulties with concentration, short-term memory, comprehension and the inability to think clearly. Fatigue limits or prevents activities in the home as well as leisure activities and restricted social relationships with friends and family.²⁹

IA-related fatigue affects employment, including productivity and ability to work. People often find that employers and colleagues have a limited understanding of their symptom.^{29 31-34} They try to take breaks and relax during the day, plan and prioritise, ask for help or divide tasks over several days to match their energy level.^{23 35} Even with some strategies in place, they report sometimes needing a full day per week to recover from activities that take energy. Overall, IA-related fatigue is experienced as a challenging symptom, which affects all areas of people's daily lives.

Evidence of mechanisms and models of fatigue in IA

As we have seen from the evidence on living with fatigue, it is rare for patients to experience professional support for their fatigue.^{24 36} One possible reason for the lack of dialogue about fatigue

in IA is limited understanding of the mechanisms involved. Research has investigated the role of potential factors, including physical functioning, psychological functioning, medical status, comorbidities and symptoms, and demographic factors, such as age and gender. The results are equivocal, although there is growing consensus that psychosocial variables are influential.³⁷

In a study examining the physical and psychosocial correlates of fatigue in RA, the authors found that those with severe fatigue scored worse on all the psychosocial items that were measured, compared to those without severe fatigue. This included pain severity, role functioning, depressive mood, self-efficacy, worry, helplessness and non-restorative sleep.⁵ Predictors of levels of fatigue in people with RA have also been examined using Leventhal's Common-Sense Model (CSM).³⁸ The CSM states that cognitive representations of an illness/health condition influence how people cope, which then affects their health outcomes. Data were collected from 114 people with RA (73.7% women) at baseline and one year later.³⁸ This information included employment status, pain, impact of disability, sleep disruption frequency, depressed mood, perceptions of the consequences of RA, arthritis self-efficacy and attempts to manage RA by praying/hoping. The researchers found that a baseline perception that RA has severe consequences and is uncontrollable predicted greater fatigue after one year but that this relationship was not mediated by praying or hoping.³⁹ There is further support for the role of psychosocial variables in pSS-related fatigue. In a study which examined cross-sectional data from 608 patients from the United Kingdom Primary Sjögren's Syndrome Registry, pain, depression and daytime sleepiness scores were closely associated with physical and mental fatigue (all $p \leq 0.0001$). These effects were observed even after adjustment for comorbidities associated with fatigue or medications associated with drowsiness.⁴⁰

Hewlett et al. propose a conceptual model that includes three domains, each of which could contribute to fatigue in RA.¹⁹ First, disease-related factors such as inflammation, anaemia and cortisol response can play a part. Second, cognitive, emotional and behavioural factors, such as depression, health beliefs, low mood and activity patterns, can be involved. Third, contextual factors might be salient. These range from managing co-morbidities, to work and caring responsibilities. Any combination of these factors may predict, trigger or maintain fatigue. Over time, this combination may vary in response to changes in an individual's RA symptoms and treatment, their psychological well-being or contextual factors, such as circumstances at home or work. The concept of complex factors influencing fatigue is supported by a recent systematic review in which the authors proposed a network model, encompassing multiple and mutually interacting biological, psychological and social factors.³⁷ Findings from the systematic review indicated correlations of fatigue with physical disability,

poor mental well-being, pain, sleep disturbance, depression and anxiety. For the most part, these correlations remained significant in multivariate analyses, suggesting partly independent influences on fatigue and differences between individuals. This network model assumes that relationships between the biopsychosocial factors are dynamic and reciprocal, with mutually influencing pathways. A second assumption is that individuals differ in relation to the factors involved in their fatigue, as well as in the importance of both the weight of these factors and the strength of the relationships between these factors. Like Hewlett et al.'s conceptual model, the network model supports the idea that fatigue is not a single construct but rather a multidimensional concept. There is also qualitative evidence to support the idea of individual differences in the causes of fatigue, including a study with ten people with AS who completed a seven-day diary and participated in a semi-structured interview to explore their fatigue. While descriptions of the symptom were similar between individuals, perceived causes of fatigue varied. They included stress, depression, pain, weather, poor sleep and work.⁴¹

While these conceptual propositions seems logical and comprehensive,^{19 37} a systematic review of epidemiological studies investigating fatigue determinants in RA only identified elements from the cognitive, emotional, behavioural and the contextual domains; and a lack of associations with biomedical factors.⁴² Some health professionals may be surprised at the absence of evidence to support the relationship between fatigue in RA and levels of inflammation. However, data from epidemiological research has found that rates of fatigue are similar between RA and some types of non-inflammatory arthritis, such as osteoarthritis (OA).⁴³ In addition, fatigue can be a significant symptom in people with RA even when there is no or minimal disease activity. In the UK's RA biologics register, 62% reported clinically relevant fatigue at one year despite reaching remission.⁴⁴

Overall, the evidence about causes of fatigue in IA offers a mixed picture. Fatigue is likely to be multidimensional and driven by factors that differ between and within individuals over time. It suggests that we should focus research on individual-specific networks of biopsychosocial factors that maintain fatigue and we should tailor interventions that target the influencing factors most relevant to that person. This is important because even though the mechanisms are not fully understood, there is evidence that the associations of fatigue with factors that are amenable to behaviour change are moderate to high.³⁷

Selecting a patient reported outcome measure and assessing fatigue with patients

To be able to target and evaluate interventions, it is important to measure fatigue with appropriate patient reported outcome measures (PROMs). PROMs can be used within consultations to screen for

problems, monitor symptoms over time, promote patient-centred care and to involve patients in decision making about their own treatment.⁴⁵ In addition, they can be used as a discussion tool within a consultation to enhance communication between healthcare professionals and patients^{46 47}(see section on **Communication skills for health professionals**).

When selecting a tool to measure fatigue, healthcare professionals should consider whether they require a single item screening tool, a global score captured by a multi-item fatigue PROM or a multidimensional measure which captures scores for different fatigue domains, such as mental and physical fatigue.⁴⁸ For example, if a multidimensional tool were to identify that physical fatigue is problematic for an individual but mental fatigue is less of an issue, this information could be used to individualise support on the basis of shared decision-making between the patient and the healthcare professional. Below are examples of fatigue PROMs used in clinical practice with patients who have IA. Some fatigue PROMs are disease specific, while others are generic. The psychometric properties are not fully explored here and not all the measures have been fully evaluated for all IA populations. In addition, it should also be noted that not all these PROMs are available in a range of European languages. For detailed information, these measures have been critically evaluated by Hewlett et al.⁴⁸

Single Item Fatigue Measures

Visual analogue scale (VAS)

- A 10cm/100mm horizontal line which measures fatigue severity or intensity of fatigue. It can be used as a screening tool and to detect changes in fatigue over time and takes under one minute to complete. The wording used as end points or anchor statements can vary.

The Bristol Rheumatoid Arthritis Numerical Rating Scales (revised) (BRAf-NRS V2)^{28 49 50}

- RA-specific measures containing three single item 0-10 numerical rating scales which capture fatigue severity, fatigue effect and fatigue coping. Each NRS takes under one minute to complete.

Global Measures of Fatigue

*Fatigue Severity Scale (FSS)*⁵¹

- A nine-item measure which includes physical, social and cognitive effects of fatigue to provide a global score. The measure takes around 2-3 minutes to complete.

*Multi-dimensional Assessment of Fatigue (MAF)*⁵²⁻⁵⁴

- A 16-item RA-specific PROM which covers four dimensions of fatigue (severity, distress, interference in activities of daily living and frequency) to provide a global score (Global Fatigue Index). The measure takes around 5-8 minutes to complete.

*Functional Assessment Chronic Illness Therapy (Fatigue) (FACIT-F)*⁵⁵

- A 13-item measure that provides a global score and takes around 2-4 minutes to complete.

*Short Form 36 Vitality Subscale (SF-36 VT)*⁵⁶

- A subscale that forms part of the SF-36v2, a multi-dimensional measure of general health status. The SF-36 VT has four items covering energy and fatigue and the scores provides a single vitality score. The subscale takes a minute to complete. However, it is administered as part of the larger SF-36v2 which takes up to 10 minutes to complete.

Multi-dimensional fatigue PROMs (generic)

*Chalder Fatigue Questionnaire (CFQ)*⁵⁷

- An 11-item measure that provides a global fatigue score as well as two subscale scores (physical and mental fatigue). It takes around 2-3 minutes to complete.

*Multi-dimensional Fatigue Inventory (MFI)*⁵⁸

- A 20-item measure that provides five sub-scale scores (general fatigue, physical fatigue, reduced activity, reduced motivation). It takes around 3-4 minutes to complete.

Multi-dimensional fatigue PROMs (disease specific)

Bristol Rheumatoid Arthritis Fatigue Multi-dimensional Questionnaire (BRAFM-DQ)^{28 49 50}

- A 20-item measure that provides a global fatigue score as well as four sub-scale scores (physical fatigue, living with fatigue, cognitive fatigue and emotional fatigue) and takes 4-5 minutes to complete.

*The Profile of Fatigue and Discomfort (PROFAD)*⁵⁹

- A measure designed for use in pSS. It comprises 16 items which measure aspects of fatigue. The scores from these items can be used to measure six facets of fatigue (need rest, poor starting, low stamina, weak muscles, poor concentration and poor memory). Domain scores for somatic and mental fatigue can also be calculated.

Medical assessment

Potential reversible causes of fatigue should be considered during assessment. This might include a review of medications which may be exacerbating fatigue symptoms or inducing daytime sleepiness. Other medical assessments and subsequent interventions should include identifying and treating comorbidities such as anaemia or metabolic and endocrine abnormalities, or other health conditions such as cancer or diabetes, as well as assessing for pain, sleep disturbances (including insomnia and obstructive sleep apnoea (OSA)), low mood and anxiety (see section on **Other interventions that potentially impact fatigue**). Some rheumatic diseases, including pSS are associated with dysregulation of the autonomic nervous system, including impaired blood pressure response to standing.⁶⁰ Autonomic dysfunction is associated with fatigue and addressing vasovagal symptoms either using purely a non-pharmacological approach, or a non-pharmacological approach in combination with medication, may help to improve the severity and impact of fatigue in these patients.^{61 62}

Social situation, family support and lifestyle assessment

We recommend a general assessment of a patient's social situation and daily function, including how their function may fluctuate according to their fatigue levels and other life demands. This assessment should include determining who they live with, expected roles within the household, what they need to do as part of their day, and determining whether they have had to take time off work or cancel other activities due to their fatigue. In addition, patients can be asked, in the context of living with their fatigue, how well they feel they are able to carry out their work, domestic tasks, self-care activities and leisure, including exercise and social activities. The Canadian Occupational Performance Measure is a semi-structured interview tool which is useful for exploring these areas.⁶³ The balance of activities in a person's life can be explored further with the Occupational Balance Questionnaire.⁶⁴ Reflections on the responses from these measures can be used when supporting a patient to set goals during treatment (see section on **Non-pharmacological interventions to reduce fatigue: clinical practice**).

Sleep assessment

Perhaps unsurprisingly, there is a relationship between sleep disturbances and fatigue in IA.^{65 66} Therefore, addressing sleep disturbances may contribute to an improvement in fatigue.⁶⁷ Primary sleep disorders, including OSA, require specialist assessment and care. Snoring and excessive daytime sleepiness can be an indication of OSA.⁶⁸ Patients should be asked if they have any issues with snoring or struggling to breathe during the night. If possible and appropriate, it is useful to have a partner present when asking these questions. Daytime sleepiness can be measured with the Epworth

Sleepiness Scale (ESS),⁶⁹ which can be used as a screening tool for primary sleep disorders including OSA.⁷⁰ Any suspicion of a primary sleep disorder warrants a referral to a sleep specialist for further evaluation. A sleep diary can be a useful tool to identify symptoms of insomnia, and detect difficulties with sleep onset, night awakenings, sleep efficiency (percentage of time spent in bed asleep) and total sleep time.⁷¹

Depression

As depression is associated with fatigue, early recognition and intervention are essential.^{40 72} The Hospital Anxiety and Depression Scale is a useful 14-item tool which can be used to detect depression and anxiety in patients.⁷³ If depression is detected during a fatigue assessment, appropriate management should be arranged in consultation with the patient and their clinical team. Some antidepressant medications are associated with side effects of drowsiness and fatigue and these possible side effects should be considered during assessment or by members of the clinical team who may be considering a pharmacological intervention for low mood.

Pain

Pain is a dominant feature of IA⁷⁴ and is associated with fatigue in RA,⁷⁵ SLE,^{76 77} pSS,^{40 78} and AS.⁷⁹ Supporting a patient with managing their pain may therefore have a positive impact on their fatigue. A discussion with the patient to identify whether they perceive a relationship between these symptoms may be helpful when developing a management plan. It is also worth considering any drowsy side effects of pain management medication.

Non-pharmacological interventions to reduce fatigue: the evidence base

To address the potentially complex and multifactorial nature of fatigue, it is likely that a multidimensional approach incorporating pharmacological and non-pharmacological interventions is the best management strategy.^{80 81} Psychosocial interventions, such as self-management programmes, cognitive-behavioural approaches and lifestyle interventions, or interventions based on physical activity have all been proposed as potentially beneficial.^{19 82-84} A Cochrane review⁸³ evaluated the benefits and harms of non-pharmacological interventions for the management of fatigue, specifically in adults with RA. The majority of the 24 included studies investigated physical activity interventions (n=6) or psychosocial interventions (n=13) with meta-analyses demonstrating statistically significant small beneficial effects on fatigue for both intervention categories. In terms of quality, the physical activity evidence was moderate and the studies investigating psychosocial interventions were considered low quality. A key recommendation from the review was the need to

design interventions specifically for fatigue management. A more recent systematic review investigating the effects of land based aerobic training on RA fatigue reported similar findings.⁸⁵ So far, research investigating non-pharmacological interventions for fatigue management in people with IA has focussed mainly on physical activity and psychosocial approaches. A few other non-pharmacological interventions have been investigated with variable effects on fatigue. The following provides a summary of recent evidence within each of these non-pharmacological categories.

Physical activity interventions

For people with RA, Durcan et al. investigated a 12-week home exercise plan that was individualised to target functional limitations identified by the participant.⁸⁶ The exercise plan included resistance exercise undertaken three times per week as well as range of movement and light to moderate intensity walking undertaken daily. The control arm received standard care only. Results demonstrated significant between group differences in change of fatigue at 12-weeks in favour of the intervention.

A 16-week supervised walking programme for women with primary pSS was compared to a control arm that were advised not to undertake any regular exercise.⁸⁷ The walking intervention consisted of three supervised sessions per week with increasing duration. There was a significant difference between study arms over time for fatigue, in favour of the intervention arm. This supported earlier pilot study findings in which women with pSS undertook Nordic walking three times per week for 45 minutes with one of the three sessions supervised.⁸⁸ In comparison to a control arm that was instructed to carry out low intensity exercise at home, the intervention group demonstrated a significant improvement in fatigue at 12 weeks, as measured using a VAS.

For those with SpA, Sveaas et al. investigated a 12-week high intensity aerobic and strength training programme.⁸¹ Participants in the exercise arm carried out twice weekly supervised high intensity aerobic interval training and strength exercises as well as once weekly unsupervised aerobic training. In comparison to the control arm that received standard care there was a significant treatment effect for fatigue in favour of the intervention. Another recent pilot study in people with axial SpA investigated the effect of Baduanjin qigong (exercise techniques that alternate relaxed movement with stretching and strengthening) in comparison to a control arm.⁸⁹ Findings demonstrated clear trends for improvement in fatigue in the exercise arm compared to a control arm, suggesting that further research is warranted.

Taken together these studies indicate that a wide range of moderate and high intensity physical activity interventions can produce short term benefit for fatigue in a range of IA conditions. None of the studies mentioned above included a health behaviour change component to promote long term engagement with the activities and no long term follow up measures were reported. It should also be noted that while fatigue was included as an outcome, there was no reference to fatigue mechanisms in the design or implementation of the interventions at an individual level.

Additional studies that have investigated the effect of a physical activity intervention with a supporting health behaviour change component include Thomsen et al. in which individual counselling and SMS reminders (texts) aimed to reduce daily sitting time in people with RA.⁹⁰ At the end of the 16-week intervention there was a significant improvement in fatigue in the intervention arm compared to the usual care control arm. It is possible that an intervention to reduce daily sitting time would be more acceptable to people experiencing fatigue than an intensive home exercise programme and as a result more likely to be sustained long term. However, further research with long term follow up is required to explore this possibility.

A pedometer intervention that aimed to increase physical activity by people with RA was investigated by Katz et al.⁹¹ One arm received the pedometer with daily step count goals and a second arm received the pedometer with no specified goals. This was in addition to a control arm that did not receive a pedometer. At the end of the 21-week intervention period there was a reduction in fatigue in the pedometer and pedometer plus step count arms, but this was not significantly different to the control arm. It should be noted however, that the target sample size was not reached which could explain the lack of significant effect.

Feldthusen et al. investigated a person-centred physical therapy intervention for people with RA that focused on health enhancing physical activity and balancing life activities.⁹² They suggested that this approach could strengthen confidence and resources to control fatigue as well as condition related symptoms associated with fatigue. There was a significant improvement in fatigue at the end of the 12-week intervention compared to the control arm which remained significant at six months.

Psychosocial interventions

In relation to the psychosocial interventions, most of the research evidence is specific to RA. A recent study by Hewlett et al. investigated the effect of a six-week group course delivered by rheumatology teams using cognitive behavioural approaches on fatigue impact.⁹³ The intervention aimed to address

'behaviours likely to be related to fatigue and their underpinning thoughts and feelings'. There was a significant reduction in fatigue impact at six months in the 'Reducing Arthritis Fatigue' intervention arm compared to the control arm. This difference remained significant at the two year follow up time point.

Ferwerda et al. also recruited people with RA to complete at least one of four internet-based cognitive behavioural intervention modules with fatigue being the focus of one module.⁹⁴ Not all participants completed the fatigue module and despite fatigue being identified as a joint primary outcome, the overall purpose of the intervention appeared to be reduction of distress. At one-year follow-up, there was a non-significant reduction in fatigue over time for the internet-based cognitive behavioural intervention arm compared to the control arm. However, it should be noted that only 37 of the 62 participants in the intervention arm completed the internet-based fatigue module.

While recent studies have focussed on cognitive behavioural approaches, earlier studies have suggested benefits of other approaches for the management of fatigue in people with RA. Those indicating the largest effects for fatigue include benefit finding and expressive writing interventions,⁹⁵ lifestyle management,⁹⁶ and a mindfulness-based group intervention.⁹⁷

Other non-pharmacological interventions

Gok Metin & Ozdemir investigated an aromatherapy intervention and a reflexology intervention for people with RA.⁹⁸ For aromatherapy, the oils were included on the basis of their active ingredients and proposed physiological effects. Results showed a significant reduction in fatigue over time for both intervention arms compared to the control arm, with the reflexology arm demonstrating greater reduction than the aromatherapy arm. However, there were some limitations to this study including a lack of assessor blinding, the absence of a long term follow up, and no active control arm. Therefore, further research is necessary before aromatherapy or reflexology can be recommended as an intervention for fatigue in adults with RA. Other non-pharmacological interventions that have shown some promise and are worthy of further investigation include adoption of a Mediterranean diet,⁹⁹ Omega-3 fatty acid supplementation for people with RA,¹⁰⁰ and vagus nerve stimulation for people with pSS.¹⁰¹

We established earlier in the paper that fatigue is a complex and multidimensional symptom that is likely to be driven by a range of factors that vary between individuals. In addition, the evidence suggests that psychosocial factors play a role in many people's fatigue. Therefore, people with IA may

benefit from interventions that target factors such as pain, poor sleep and depression. Earlier we discussed assessment, and later we will consider how factors such as sleep and depression can be addressed in clinical practice. Here, we describe the evidence for some potentially helpful non-pharmacological interventions.

Cognitive behaviour therapy for insomnia (CBT-I) may be a useful intervention for people with co-morbid insomnia and IA and there is some evidence for its effectiveness at improving insomnia symptoms in other rheumatological conditions including OA and fibromyalgia (FMS).^{102 103} A CBT-I intervention comprises of several key components, which are usually delivered over 6-8 sessions by a trained therapist who receives the appropriate supervision. Components include sleep education and sleep hygiene; sleep restriction; stimulus control; cognitive control; thought control/distraction; paradoxical intention and dealing with dysfunctional beliefs/cognitive restructuring.^{104 105}

Depression is common in rheumatic diseases.¹⁰⁶⁻¹⁰⁸ It is important that health professionals are able to identify signs of depression and low mood, and that those affected are able to access appropriate interventions.^{109 110} Some components of recommended treatments for depression, such as behavioural activation (e.g. identifying valued life activities and goal setting) and cognitive behavioural therapy (e.g. graded activity), are like those offered for fatigue management.¹¹¹ Therefore, it is possible that an intervention that includes some components of an evidence-based psychosocial intervention for depression, may have a positive impact on a person's fatigue. However, this cannot be assumed.

Pain management strategies should follow the appropriate guidelines and may include pharmacological and non-pharmacological interventions. Some of the recommended non-pharmacological interventions for pain in arthritis⁷⁴ share similarities with fatigue management strategies (e.g. activity pacing).¹¹² Therefore, some non-pharmacological fatigue management strategies may help with pain management and vice versa. Health professionals might also be able to transfer their training and skills between supporting pain and fatigue management.

The ethos of non-pharmacological interventions to reduce fatigue

Overall, evidence suggests that non-pharmacological interventions can have a beneficial effect on self-reported fatigue in people with IA. Key to successful multi-disciplinary non-pharmacological interventions is empowering patients to self-manage their health condition, with a view to improving symptom control, preventing long-term complications and developing coping strategies. In the UK,

the National Health Service (NHS) Five-Year Forward view recognises “that patients' own life goals are what counts” and individuals need to be empowered to manage their own conditions.¹¹³ It is increasingly acknowledged that effective health professional–patient partnerships involve shared decision-making and self-management interventions to deliver better outcomes and improved quality of life with potential cost savings across the health and care system.¹¹⁴ However, to successfully manage their health, people need information and tools to develop and maintain self-management skills.^{115 116} One potential area to explore is the role of mobile technology, such as pedometers and web-based applications.¹¹³ Incorporating technology could increase benefits and help scale up delivery of self-management tools to meet the health needs of those with IA and reduce pressure on services.

Non-pharmacological interventions to reduce fatigue: clinical practice

The first step to providing support in clinical practice is identifying that fatigue is an issue for someone and being open to working with them on management strategies.¹⁰⁹ While fatigue is a common and debilitating symptom for many people with IA, they can be reluctant to discuss their fatigue during their clinic appointments, as there is a perception that this symptom will be dismissed by their healthcare professionals.²⁴ The failure of healthcare professionals to acknowledge fatigue and its impact on daily life can exacerbate any psychological distress and impact on patients' confidence.¹¹⁷ Findings from a Dutch study demonstrated that patients may use implicit cues about their fatigue during a consultation, rather than being explicit about their concerns.¹⁸ Having the symptom of fatigue taken seriously, being believed and having appropriate support to self-manage this symptom are top priorities for patients.¹¹⁸ A UK multicentre survey investigating patient preferences for psychological support in IA found that 82% of patients wanted support with managing the impact of both pain and fatigue,¹¹⁹ which suggests that this need is currently not being addressed. It is therefore important for healthcare professionals to ask patients about fatigue directly during consultations, rather than putting the onus on the patient to spontaneously mention it.¹⁸

Techniques and tools for clinical practice

It is important for members of the rheumatology team to validate and acknowledge patients' experience of fatigue and the impact that this symptom has on their lives. A qualitative study which explored the impact of written information about fatigue using an education booklet, concluded that written information that was provided by a health professional and followed by a conversation which included some guided reflection, was sufficient for some patients to make behaviour changes to help manage their fatigue.¹²⁰

Communication skills for health professionals

The interaction between health professionals and patients can play a key role in the provision of fatigue support.¹²¹ A collaborative dynamic that values both professional expertise and lay experiential knowledge can help patients to acquire the information and skills that they need to actively manage their health.¹²² Approaches such as motivational interviewing (MI) and Socratic questioning (also known as guided discovery or ‘Ask don’t tell’) can be helpful and have been used in psychosocial interventions for RA-related fatigue.^{26 82 93} MI is an evidence-based way to discuss behaviour change that promotes patients’ autonomy and decision-making.¹²³ The focus is on eliciting patients’ thoughts and feelings about behaviour change and guiding discussions to resolve their ambivalence. A key tool is the use of ‘OARS’ questions (open-ended, affirmations, reflections, and summaries).¹²⁴ Likewise, Socratic questions are curious and non-judgemental (e.g. ‘How is this a problem for you? Can you give me an example?’) and designed to explore assumptions (e.g. ‘Let me check that I understand this’). These are questions that the patient has the answers to, that draw attention to relevant issues and information, that move from concrete to abstract, and that help the patient learn to reflect.^{125 126}

Activity diaries

Due to the unpredictable nature of RA fatigue, monitoring tools can be helpful. One example is an activity diary to monitor energy expenditure. Patients can use the diary to record their activity levels, rest, sleep and to make a note of any fatigue “crashes” when any activity had to stop due to overwhelming fatigue. The completed diary can then be used with a health professional in a guided reflection to look for patterns in activity levels and fatigue symptoms and to identify behaviours that might be driving or exacerbating crashes. This tool can also be used to prospectively plan, for example allocating times for rest as part of pacing activity during the week. Activity diaries are used in fatigue self-management interventions and have been highlighted by patients as helpful for self-management.^{26 82 93}

Problem solving

Completing a daily activity diary can help patients analyse how they do activities. As an example, if a person spends every morning doing the same activity, repetitive task, or in the same working position, they might spend the afternoons dealing with an exacerbation of pain and discomfort as a result. A patient can be supported to consider the following question, “When a task or an activity causes a problem, how might you be able to do it differently?”. The activity diary can show patterns in boom and bust behaviours (e.g. weekends spent recovering from a working week, or ‘crash’ periods after a task has been completed).

Pacing

Patients can break up an activity into smaller, bite-sized chunks, spreading them out over a period and interspersing them with short, regular rests. For example, rather than tackling a cleaning task in one go (such as the entire home), it can be divided up into zones (such as rooms) or smaller tasks (such as dusting) and one zone or task completed before taking a break. Activities can also be paced over a longer period, such as a week, and interspersed with different types of activity and rest. It is helpful for patients understand the importance of taking a break before the fatigue sets in.

Prioritising

Patients can write down tasks and activities that need to be done in a day or a week and rank them for importance. Patients can decide whether each task needs to be done, whether it can be delegated or whether someone can help with it. One challenge when patients prioritise is that tasks which could be viewed as less important, may be tasks which are meaningful and fulfilling. For example, patients may prioritise work or looking after family members above their own leisure activities. It can then be helpful to have exploratory discussions about the choices that the patient makes and whether they want to consider the inclusion of some relaxing and enjoyable activities that might be restorative and nourishing.

Planning

Patients can use the prioritised task list and a blank activity diary to plan activity over the next week or few days. By using a combination of problem solving, pacing techniques and prioritising, patients can plan for essential tasks to be interspersed with regular planned rests and leisure activities.

Goal setting

Supporting patients to set goals as part of shared decision making can be a useful part of fatigue management. One approach is SMART (specific, measurable, achievable, realistic, and timely/time limited), which can be helpful for goals that relate to task completion and behaviour.¹²⁶ However, if the goals concern knowledge, skills, abilities and strategies which focus on learning, a MEANING approach may be more appropriate.¹²⁷ Goals should be meaningful (M), health professionals should engage (E) patients to establish trust and discuss what is meaningful, short term goals should be anchored (A) to what is meaningful and to the interventions to reach long term goals, patients and health professionals should negotiate (N) the desired level to aim for and create motivation and hope. Patients and health professionals should try to bridge the intention-implementation (I) gap and consequently, setting new goals (N) should be an on-going process which provides an opportunity for

patients to develop a strategy and to learn over time. Finally, goals (G) should relate to theoretically informed behaviour change. The Canadian Occupational Performance Measure is a semi-structured qualitative interview tool which can also be useful to help patients identify short and long-term goals in these separate areas to introduce some occupational balance.^{63 128}

Grading activity

This is when a patient selects an activity which they would like to do more of, or to re-introduce if they have been stopped due to their fatigue (see goal setting). Activities can be graded up in time, effort/resistance, complexity and speed. However, any chosen activity should be graded up gradually and maintained before another increase is made. For example, if a patient can concentrate on reading for 15 minutes without exacerbating their symptoms, they may like to try and extend this by a couple of minutes.

Physical Activity

Being physically active can help to reduce fatigue although it can be difficult to get started. It is important to start with small, achievable activity targets with short bouts of moderate physical activity. There is no clear evidence for one type of activity being better at reducing fatigue although finding something that the person enjoys is important. It may also help to have an exercise buddy to help with motivation.¹²⁹ Over time gradually increase the duration and/or intensity of the activity as it becomes easier. During periods of flare or illness, or if fatigue is exacerbated by the activity, it may be necessary to drop back to a previous level. This should not be viewed negatively and when possible continue to progress the activity again.

Assertiveness and communication training for patients

Fatigue is an invisible symptom. Therefore, it is essential for someone with fatigue to be able to communicate their needs appropriately.¹²⁶ Education on different communication styles, for example being assertive as opposed to being manipulative, passive or aggressive, can help someone to communicate their needs appropriately. Similarly, being able to “say no” is a useful skill, which can help prevent patients from feeling overwhelmed, upset or exhausted from taking on too much. Supporting patients to reflect on their assertiveness and communication skills can include discussions about their beliefs and established roles and how they influence their current communication styles.

Mindfulness

Stress and bodily reactions to stressors can negatively affect patients' physical and mental fatigue. Mindfulness is an approach which has been used primarily for stress-reduction. It is a technique where the person brings their awareness to what is going on in the present moment, including their bodily sensations and reactions, without being judgemental.^{97 130 131} The practice of mindful meditation cultivates attentional focus and stability by directing the mind to remain connected to the experience of the present moment. Attention is usually sustained by concentrating on the breath.

Setback planning

Accepting that setbacks and fatigue flares are likely to happen can be a positive step for a person with IA, and advance planning on how to deal with these situations can be helpful. Being aware of triggers that can cause a setback (such as a flare of symptoms, viral illness, stress, deadlines, periods of over-activity, and other life events) can help a person anticipate when a setback might be likely to happen. However, it is important to recognise that setbacks can also occur without any obvious reason. It may be useful to work with "if – then" to try to reduce the intention-implementation gap. This can be "if your child is sick and you cannot exercise as planned that day, then ...".¹²⁷ Whatever the trigger, if a person with IA has a plan in place, it can help them to deal with the challenge proactively. The plan may vary depending on the trigger, for example, a viral illness may require a few days of rest. A plan may include reducing exercise and increasing the use of relaxation for a period. It may also be helpful to use some of the previously mentioned strategies; e.g. keep an activity diary for a short period and use it to plan a new schedule with planned rests.

Workplace considerations

Fatigue has been found to have a significant and independent effect on absenteeism, presenteeism, productivity loss, and activity impairment.³³ Reasonable adjustments can be made in the workplace to manage the fatigue associated with IA and will need the patient to discuss their requirements with their occupational health department and their manager. A clinical intervention can include a letter of support outlining some suggestions for reasonable adjustments. This could include flexible start and finish times, working from home, regular breaks, the ability to switch tasks and appropriate seating. Discussions about joint protection and ergonomics may also be helpful.^{34 132}

Conclusions

In summary, research evidence and clinical practice have established that fatigue is a common symptom affecting many people with IA. It can impact all realms of daily life, including relationships, work, social activities and emotional well-being. The causes of fatigue in IA remain unclear, although

there is growing consensus that it is likely to be multidimensional and driven and maintained by several factors that differ between and within individuals over time. Currently, the strongest evidence is for the role of psychosocial factors. While limitations remain in relation to the evidence to support the use of non-pharmacological interventions in the management of IA-related fatigue, they have the potential to benefit people with IA. In relation to psychosocial interventions, there is evidence that cognitive behavioural approaches can reduce the impact of RA fatigue, while for physical activity there is strong evidence of short-term benefit with further research needed to explore long term effects. A range of helpful approaches and tools are available for health professionals to use in clinical practice. The first step is to identify and assess a person's fatigue, then to look at ways to support them to develop management strategies. This might involve targeting fatigue directly or looking at other related factors such as poor sleep, pain and depression. There is evidence to support the use of a Socratic questioning or 'Ask don't tell' approach and using cognitive behavioural tools such as activity diaries, and for promoting the benefits of physical activity. Fatigue support should be based on a collaborative approach between health professionals and patients, with the aim of empowering patients to feel more in control of their IA and equipped to cope with the challenges of an unpredictable and fluctuating symptom.

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