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## Rheumatic disease and fatigue: Participants' experiences of an activity-pacing group

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### ABSTRACT

**Background:** Fatigue is a common symptom of inflammatory rheumatic disease and has a great impact on everyday life. Activity-pacing is proposed as an intervention to increase participation in meaningful activities.

**Aims:** To explore participants' experiences with an activity-pacing group, how participants perceived self-managing everyday life after group attendance, and their reflections on unmet needs that could enhance self-management of everyday life with fatigue.

**Materials and methods:** Semi-structured interviews were conducted with 10 participants who had attended an activity-pacing group. Thematic analyses were conducted.

**Findings:** Prior to group attendance, the participants expressed an awareness of their lack of knowledge of fatigue. Through group attendance, they increased their understanding of fatigue and their ability to apply strategies to better manage everyday life. Participants found it difficult to balance their energy use and realised that implementing activity-pacing strategies takes time. Therefore, they requested follow-up sessions with the activity-pacing group. They also desire that rheumatologists pay more attention to and acknowledge fatigue.

**Conclusions and significance:** Enhancing the understanding of fatigue and how to manage everyday life with fatigue, appears to be important. Group interventions led by occupational therapists and with a focus on activity-pacing may be a suitable approach. Follow-up sessions are recommended.

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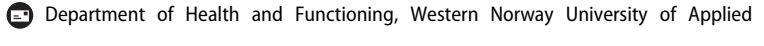
## Introduction

Inflammatory rheumatic diseases (IRDs), such as rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, systemic lupus erythematosus, and Sjögren's syndrome are common chronic conditions. Rheumatoid arthritis is the most common, with a global prevalence of 0.46% of the population [1]. The most frequently reported symptoms of IRDs are pain, fatigue, swelling and stiffness of joints, where fatigue is experienced by 35–82% [2–4]. There are gender and age differences; the impact of fatigue on everyday living seems to be greater for young women [5,6].

Fatigue is a subjective feeling that may have a physical, cognitive, emotional, and cognitive impact. It is

described as overwhelming and uncontrollable, ignored by health professionals, and can only be partly related to objective clinical measures of disease activity [7]. Beyond the assumption that the diagnosis itself can lead to fatigue, the cause is unknown [4]. Psychological and social factors may also influence the degree of fatigue experienced [8,9]. In addition to pain, fatigue is the symptom perceived to have the greatest negative impact on everyday life for people with IRDs [7,10]. Fatigue seems to affect social life [7,10,11], leisure, work participation [7,12,13], and quality of life [9].

Pharmacological treatment does not seem to improve fatigue for everybody, and therefore, non-pharmacological approaches may be necessary [4]. Approaches guiding and training those with IRDs and

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fatigue to better self-manage everyday life have been recommended [7,14]. Self-management refers to the management of symptoms, treatment, physical and psychosocial consequences of living with a chronic condition, and entails an active, continuous, and interactive process that requires multidimensional strategies within the context of a person's everyday life [15,16]. Various strategies are used to self-manage everyday life with fatigue and IRDs [7,10,12,17], often through trial and error [11]. Acceptance of fatigue, an optimistic attitude, and gaining support and discussing fatigue-related challenges with health professionals, are factors emphasised by people suffering from IRDs [7,18]. Strengthening self-management skills to help people with IRDs to handle everyday life is recommended [19], including approaches for fatigue management [14]. Even though managing fatigue on one's own has been reported as challenging, fatigue-related challenges are seldom discussed with health professionals [7,20].

Approaches based on cognitive behavioural therapy (CBT) [19] and activity-pacing are recommended forms of interventions [21]. However, there is a lack of knowledge regarding which approach is perceived by the patients as being most useful [12,22]. A six-week CBT intervention showed an effect on the acceptance of fatigue, and on the management of everyday life for people with rheumatoid arthritis [23,24]. The purpose of activity-pacing for people with IRDs is to enhance participation in meaningful activities, usually requiring a change process. Furthermore, activity-pacing involves enhancing one's awareness of how to influence and manage everyday life, considering which activities are important, planning and prioritising activities, and trying to balance the use of energy in one's performance of daily activities [25]. It is necessary to explore whether activity-pacing can affect perceived fatigue and activity performance in those with IRDs, and to investigate their perceptions of activity-pacing interventions [25]. Therefore, this study aimed to explore: (1) participants' experiences with an activity-pacing group, (2) how participants perceived self-managing everyday life after group attendance, and (3) their reflections on unmet needs that could enhance self-management of everyday life with fatigue.

## Material and methods

### Design

In order to explore participants' experiences and reflections, this study employed a qualitative design.

Individual interviews were chosen in order to gain an in-depth understanding of the participants' experiences and reflections [26] and because we aimed to conduct the interviews in connection with each participant's follow-up appointment. Data-driven inductive thematic analyses were conducted in order to capture the participants' experiences and reflections [27].

### Participants

Patients with IRDs who had attended an activity-pacing group as part of their rehabilitation programme at a Department of Rheumatology in specialist health service in Norway were eligible for participation. At the start of the rehabilitation programme, patients self-reported fatigue on a 0–10 numeric rating scale as part of completing the Rheumatoid Arthritis Impact of Disease (RAID) questionnaire [28]. A score of 0 indicates no fatigue and 10 indicates extreme fatigue. All those who had attended the activity-pacing group between January and June 2018, were invited to participate in the present study, regardless of their self-reported fatigue score. Eleven participants were recruited between April and November 2018, of which one withdrew prior to the interview due to personal reasons.

### Activity-pacing intervention

Based on previous research and experience, occupational therapists (OTs) at the Department of Rheumatology developed and led the activity-pacing group. The intervention is based on a quota-contingent operant approach, which emphasises identifying participants' baseline level of activity, setting meaningful and realistic goals and applying activity-pacing behaviours to adapt one's activity performance to reach one's goals. The aim of this approach is therefore to adapt participants' activity performance in order to increase function, rather than to avoid activity or reduce fatigue as a symptom [29]. The approach is in line with recommendations for activity-pacing interventions [21,25], employs elements of cognitive approaches, a biopsychosocial perspective, and focuses on self-management strategies, as emphasised in EULAR recommendations [14,19]. A biopsychosocial perspective was chosen as fatigue is influenced by multiple and interacting biological, psychological and social factors [30].

The intervention aims to enhance participants' motivation for change and enable them to better

**Table 1.** Overview of the content of the activity-pacing intervention.**Before the first group session:**

1. As part of enhancing participants' awareness of their everyday life, they complete an activity log<sup>a</sup> describing their activities and breaks in a typical week

**First group session:**

1. Focussing on enhancing participants' awareness of:
  - a. what is challenging in their everyday life
  - b. their strengths
  - c. what they want to change in their everyday life
2. Discussion of over- and under-activity, a varying level of activity and a gap between earlier and existing capacity (of activity)
3. Introduction to a biopsychosocial model
4. Evaluation of the participants' activity logs<sup>a</sup>:
  - a. what is working
  - b. which activities they perform too much/too little
  - c. what is draining the participants
  - d. which activities are prioritised by the participants; what they need to do and what they want to do
  - e. structure/organisation of everyday life; balancing activity and rest?

**Between the two group sessions ('homework'):**

1. Writing down activities that give or previously gave energy, joy, and/or well-being

**Second group session:**

1. Sharing reflections from the first session:
  - a. whether participants have started setting goals for themselves
  - b. reflections on the need for adjustments/adaptations
2. Discussion of 'homework'
3. Strategies for managing everyday life with fatigue
  - a. discussion among participants
  - b. guidance by OT: cognitive approach focussing on helpful/positive thought, introducing activity plan<sup>b</sup>, prioritising, structuring/organizing everyday life, communication with family, friends and colleagues, setting limits, delegating tasks, simplify activities, clearly expressing own needs and desires.

*Note.* <sup>a</sup>An activity log is a description of a participant's typical week, illustrating their activity performance and periods of rest. <sup>b</sup>An activity plan is a plan of how the participant wants everyday life to be, illustrating activity performance and periods of rest during a week [28].

manage everyday life. Through individual reflection, tasks and group discussions, the intervention places an emphasis on increasing participants' awareness of perceived challenges and how they can self-manage. Activity-pacing behaviours are introduced such as planning, prioritising, and breaking up tasks into manageable pieces [25]. Cognitive elements are discussed, such as the relationship between thoughts, feelings and behaviours, in addition to promoting and inhibiting thoughts. Before the first group meeting, the participants complete an activity log [31]. An activity plan [31] is completed individually in collaboration with the OT after the group sessions. Table 1 provides a description of the main content of the activity-pacing group. The intervention within the rehabilitation programme consists of two group meetings, each of which, for practical reasons, lasts one hour. The rehabilitation programme runs either for two weeks (five days of rehabilitation each week) or four weeks (two days of rehabilitation each week). The same OT leads all the activity-pacing groups.

## Interviews

A semi-structured interview guide was developed based on the authors' experiences related to fatigue and IRDs, activity-pacing, and previous research concerning these topics. Our preconception was that the activity-pacing group was valued by the participants because fatigue was acknowledged in the group discussions. However, we wanted to explore whether the approach contributed to enhanced self-management of everyday life, and to investigate participants' reflections on the organisation of the group. Since most of the authors are OTs, our understanding of living with and managing fatigue is influenced by theoretical perspectives within occupational therapy as well as Bandura's theory of self-efficacy [32] and Antonovsky's theory of sense of coherence [33].

A patient-research partner was involved in the development of the interview guide. It comprised open-ended questions to stimulate the participants into sharing their reflections and experiences without asking leading questions. The interview guide consisted of questions regarding participants' reflections

**Table 2.** Main topics of the interview guide.

## Opening questions

- How long have you experienced fatigue as a symptom of your rheumatic disease?
- How do you perceive fatigue to influence your everyday life; can you describe a typical day for me?

## Main questions

- During your rehabilitation programme you attended an activity-pacing group. Can you describe your experiences with this group intervention?
- Has anything changed since you attended the rehabilitation programme at the Department of Rheumatology?
- Can you describe a good day and a bad day?
- What is most important to you in the future?
- Can you describe what you miss/are satisfied with regarding the help you have received from health professionals until now?

## Closing questions

- Have you had any important experiences that we have not talked about?
- Do you have anything to add before we end the interview?

*Note.* The main questions primarily intend to inductively explore the aims of the study. The first of the main questions are mostly related to the first aim, whereas the other main questions are mostly related to the second and third aims.

on and experiences with the activity-pacing group, how they managed everyday life, and their reflections on unmet needs that could enhance the management of everyday life with fatigue. A pilot test of the interview guide was carried out with a former participant of the activity-pacing group (Table 2). No changes were made after the pilot test.

The first author, who had not been involved in the activity-pacing group, conducted all 10 interviews. They were conducted face-to-face, four to six months after the participants attended the activity-pacing group. Nine of the interviews took place in the hospital and one in a café, at the request of the participants. The interviews lasted for 40–70 min and an audio recording was made. Data collection ended when the interview material was considered to contain enough variety and common features to enrich the aims of the study.

### Data analysis

The recordings were imported into NVivo qualitative data analysis software (QSR International Pty Ltd. Version 12, 2018), and transcribed verbatim by the first author. NVivo was used as a tool to organise the data and the coded material in a structured way. Reflective notes were written after each interview in order to get a first impression of the interview and the topics emphasised by the participant. The first author also used the reflective notes to become more aware of her preconception prior to the analyses, by exploring what she learned from each interview and what made her curious to further explore. Further inductive thematic analyses were conducted following the phases described by Braun and Clarke [27]: (1) familiarisation with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining/naming themes, (6) producing the report.

To become familiar with the data, the transcripts of three randomly selected interviews were read by

the first and the last author. We aimed to get an impression of the content and searched for meaning and patterns in the data by separately coding the three transcripts inductively. We then discussed the content of each interview and the important participant experiences in order to determine the main topics relevant to the study. Based on this discussion, a preliminary coding scheme was developed by the first author. Examples of preliminary codes were: self-management strategies, lack of information, sharing experiences, the need for a follow-up to the activity-pacing group. The remaining transcripts were then inductively coded by the first author, using the preliminary coding scheme whilst remaining open to additional topics and codes in the data. Thereafter, the three initially-coded transcripts were re-read and re-coded in accordance with the codes generated throughout the coding process.

Next, the codes were organised into broader preliminary sub-themes and two core themes. The organisation of the core themes and the sub-themes was discussed with the co-authors and changes were made to better illustrate the relationships between sub-themes. The collated data extracts for each theme were read to ensure that they were relevant to the sub-themes in which they were organised. Finally, the entire data set was re-read to ensure that all relevant text was coded and organised into an appropriate sub-theme. The findings are presented in a descriptive manner using quotes.

### Ethical considerations

The Regional Committee for Medical and Health Research Ethics approved the study before participant recruitment (approval number 2017/1734). All participants signed informed consent forms and were informed of their right to withdraw from the study. Electronic data were stored on a secure server, and

personal data were anonymized in the transcripts and the reports.

## Findings

Two men and eight women participated in the study. See Table 3 for participant demographics and selected clinical characteristics. Participants' experiences and reflections were organised as two core themes: *Acknowledging fatigue and applying self-management strategies – it's still challenging to manage everyday life* and *Enhanced management of everyday life requires acknowledgement of fatigue and takes time*. The two core themes comprise six sub-themes: (1) *the need to be acknowledged and acknowledging living with fatigue*, (2) *strategies for living the life I desire*, (3) *concerns about activity and role performance – I really want to, but I'm not capable*, (4) *the use of energy – a balancing exercise*, (5) *rheumatologists should pay more attention to fatigue*, and (6) *a need for a follow-up and of valuing one's efforts of self-managing* (see Table 4).

### **Acknowledging fatigue and applying self-management strategies – it's still challenging to manage everyday life**

Based on the inductive analyses, this core theme concerns the participants' experiences with the

activity-pacing group and reflections on how they have self-managed after group attendance. It comprises intertwined topics structured in four sub-themes. The findings reveal that the participants have experienced a lack of understanding and acknowledging of fatigue themselves. Therefore, they emphasise the importance of the activity-pacing group, where fatigue is acknowledged both by their peers and by the OT. The group enhanced participants' understanding of fatigue, which further helped them to acknowledge that they were living with fatigue and therefore had to try out new strategies to manage their everyday activities. Furthermore, the group also contributed to an understanding of participants' abilities to better manage everyday life. However, management of everyday life with fatigue was still perceived as challenging.

### **The need to be acknowledged and acknowledging living with fatigue**

This sub-theme deals with participants' experiences with the activity-pacing group. The participants were positive with regard to the individual appointments with the OT and the activity-pacing group they had attended. There they felt that fatigue was acknowledged, both by the OT and their peers. This led to an enhanced understanding of fatigue: *'It was like someone turned on the lights, when this [fatigue] was*

**Table 3.** Participant demographics and clinical characteristics.

Participant	Gender	Age group	Diagnosis	Illness duration	Fatigue duration	Working situation	RAID fatigue score before rehabilitation
1	Female	40–59	SLE	6–8 years	6–8 years	Yes (mainly disability benefit)	3
2	Female	18–39	AS	>10 years	6–8 years	No (disability benefit)	5
3	Male	40–59	PsA	3–5 years	3–5 years	Yes	5
4	Female	18–39	AS	3–5 years	1–2 years	Yes	7
5	Female	18–39	Sjögren's Syndrome	6–8 years	3–5 years	Yes	9
6	Female	40–59	RA	9–10 years	3–5 years	Yes	6
7	Female	40–59	PMR	1–2 years	1–2 years	No (sick leave)	7
8	Female	> 60	PsA	>10 years	>10 years	No (disability benefit)	8
9	Male	40–59	PsA	>10 years	3–5 years	Yes	6
10	Female	18–39	JIA	>10 years	3–5 years	Yes (partly sick leave)	5

Note. SLE: systemic lupus erythematosus; AS: ankylosing spondylitis; PsA: psoriatic arthritis; RA: rheumatoid arthritis; PMR: polymyalgia rheumatica; JIA: juvenile idiopathic arthritis; RAID: Rheumatoid Arthritis Impact of Disease questionnaire.

**Table 4.** Overview of core themes and sub-themes extracted from individual interviews.

Core themes and sub-themes	Participant									
	1	2	3	4	5	6	7	8	9	10
<b>Acknowledging fatigue and applying self-management strategies – it's still challenging to manage everyday life</b>										
The need to be acknowledged and acknowledging living with fatigue	x	x	x	x	x	x	x	x	x	x
Strategies for living the life I desire	x	x	x	x	x	x	x	x	x	x
Concerns about activity and role performance – I really want to, but I'm not capable	x	x	x	x	x			x	x	x
The use of energy – a balancing exercise	x	x	x							x
<b>Enhanced management of everyday life requires acknowledgement of fatigue and takes time</b>										
Rheumatologists should pay more attention to fatigue	x	x	x	x				x	x	x
A need for a follow-up and of valuing one's efforts of self-managing		x	x	x	x		x	x	x	x

mentioned. Yes, thank you very much, someone finally put into words how I feel.’ (Participant 10.)

Meeting peers was also valued because the participants realised that others experienced the same challenges in their daily life, which also helped them acknowledge and accept that they were living with fatigue:

*It was very good to hear that it's not just me feeling like this. (...) And then I think it was very nice to get some perspective on how I think, what I want, and set some goals and things like that... to be a little aware... You were “pushed” a little from the others, right. (Participant 5.)*

Thus, the activity-pacing group helped the participants to put things into perspective. Listening to others’ thoughts and experiences were mentioned as helping the participants to better understand their own situation and their feelings concerning living with fatigue. They learned from each other, because ‘listening to many different thoughts enabled me to sort my own thoughts differently.’ (Participant 6.) Hearing how others managed was also perceived as having something to aim for, to achieve a sense of mastery. Therefore, several participants found the activity-pacing group to be motivating:

*I don't think you'd be as motivated by being on your own. Sharing experiences is golden. And then someone takes control of it a bit and keeps us to topic. These conversations – you learn so much from them. (Participant 10.)*

The participants emphasised that someone led the group to keep them on the topic of the discussion. They also highlighted the OT’s constructive feedback and her way of raising an issue, as this enabled them to reflect on their ability to solve fatigue-related challenges: ‘She [the OT] kind of made you reflect a little... The way she spoke. In a way, she sent the questions back to you.’ (Participant 7.) However, sharing experiences and learning from peers was perceived as different from talking to health professionals alone: ‘When you talk to health professionals, they know the basics; whatever they’ve learned from others, what’s written about this. But they don’t experience it themselves.’ (Participant 2.)

The activity-pacing group enhanced the participants’ understanding of fatigue and enabled them to acknowledge living with fatigue. The participants also reported using strategies to better manage their everyday life.

### **Strategies for living the life I desire**

After attending the activity-pacing group, some participants had become more aware of their abilities and found it motivating that they could take small steps to

self-manage everyday life. One participant had learned to identify when she could push herself a little further and when she could not. Another had started enjoying exercising regularly and felt that she benefitted from it:

*I've found an excitement about exercise I didn't know I had. And I've started exercising... So, I feel like I'm better by doing that. I still have the same pain, and the same periods of fatigue, but I feel like my days are better. I'm less tired. (Participant 5.)*

All participants reported using activity-pacing strategies to self-manage their everyday lives. The strategies most often applied were planning and prioritising. Work seemed to be prioritised by those who were working, while some tried to prioritise social activities, hiking and singing: ‘Music, that’s kind of what keeps me going. In a way, it saves me.’ (Participant 8.)

*It's work, and then... I do prioritize work because I don't feel like sitting at home and feeling sorry for myself. It's OK to go to work and do what is expected of you. Then you're also part of the social, and that means a lot to me. (Participant 9.)*

Some participants had started breaking up activities into manageable parts or saying ‘no’ when feeling too fatigued to go through with their plans. Breaking up activities enhanced some of the participants’ feelings of mastery. One participant had started taking a 10-minute break every hour to save up some energy during the day. Others distributed their activities during the week, such as: ‘I have a calendar where I write things down. If something is written on one day, then that day is occupied.’ (Participant 1.) Another participant had started recognising when she was doing too much and used her weekly days on sick leave to recover.

Getting in touch with health professionals was also mentioned as an applied strategy:

*I have a good “system” [of health professionals] now, and it helps a little too. There is one thing I am very happy about with the rehabilitation as well, then, that I got in touch with an occupational therapist. (...) And it's very nice that it's just a phone call, to get an appointment. That was great with the rehabilitation. You get some relations, some resources that can contribute... (Participant 5.)*

Despite using various strategies and focussing on positive aspects of their self-management, the participants still experienced concerns and challenges with managing their daily activities and roles.

### **Concerns about activity and role performance – I really want to, but I'm not capable**

Living with fatigue was perceived as having an impact on participants’ previous roles. Some reported having

feelings of loss, as they were unable to do some of the activities they perceived as meaningful. One participant experienced fatigue affecting her role as a mother:

*It's very, very rare that I have the energy to take her, and to play a lot with her. And that's what's on my mind the most; it's mostly dad who plays, and he's the one that takes her outdoors and things like that. But I really want to... (Participant 2.)*

Others had concerns about whether they would be able to continue working if they had children, and those who were on sick leave were anxious as to whether they would be able to return to work:

*Then I'm thinking that someday I might want to have children. But then I think that maybe I won't manage it. I'm just thinking... First, then I can't work this much, if I have a child, right? It's ok, although... (Participant 4.)*

Living with fatigue was perceived as influencing the participants' ability to manage everyday life in general. Most participants struggled to accept that they no longer had the same capabilities as they did prior to suffering from fatigue, and therefore, found it difficult to balance their use of energy in everyday life.

### **The use of energy – a balancing exercise**

Although most participants perceived changes after attending the rehabilitation programme, they still struggled to distribute their energy throughout the week: 'If I'm very energetic one day, then I'll be flat on my back the day after.' (Participant 1.) Former habits seemed to linger, despite the consequences: 'I like to get things done. I'm a bit like that. Efficiency. Yes, and then I'll just have to "crash" afterwards. It's not the best way, I know that.' (Participant 10.)

Some participants found it hard to prioritise activities; they wanted to take part in more activities than they were capable of. Therefore, it was difficult to avoid spending too much energy in one day:

*Even if I try to get my energy levels up, I always end up – every day – using far more than I have to spend, and always end up hitting the wall during the day. I get so tired, even if I've learned some techniques... (Participant 2.)*

Thus, management of everyday life with fatigue was perceived to require time to change habits, to enhance awareness of self-management strategies, and to implement these strategies.

### **Enhanced management of everyday life requires acknowledgement of fatigue and takes time**

This core theme deals with participants' reflections on unmet needs that could enhance self-management of everyday life with fatigue. It comprises two sub-themes reflecting participants' desire for rheumatologists to acknowledge fatigue as a symptom, and their perceptions of enhanced self-management requiring time to change, and therefore, a need for a follow-up of the activity-pacing group.

### **Rheumatologists should pay more attention to fatigue**

The participants reported that it was difficult to understand fatigue and to manage their everyday life with fatigue before they had been referred to health professionals who focus on how to manage everyday life with fatigue. Although some participants were satisfied with how their rheumatologists had paid attention to fatigue, most participants expressed the desire for rheumatologists to be more interested in IRD patients' stories and to acknowledge fatigue as a symptom. Some of the participants had been referred to an OT by their rheumatologist when reporting fatigue-related challenges in their everyday life, but not everyone:

*The rheumatologists could talk about fatigue more. I first heard of that word from an OT. I've been ill for 12 years and have been talking about this [fatigue] for at least seven to eight years. So why hasn't any doctor said something, when you see the doctor once every six months? You don't always feel like the doctors listen to what you have to say. (...) There are other people here that work with it [fatigue] who could have given you some time and some tips and thoughts about why you feel like that, and what we can do to make daily life a little easier. (Participant 2.)*

In addition to a desire for rheumatologists to pay more attention to fatigue, participants also expressed a need for a follow-up of the activity-pacing group to be able to further enhance their self-management of everyday life.

### **A need for a follow-up and of valuing one's efforts of self-managing**

Several participants expressed that acknowledging living with fatigue takes time, and some seemed to struggle with accepting that their fatigue as a symptom may not change. At the time of the interview, some had difficulty continuing to use strategies that may enhance their management of everyday life. Therefore, most participants expressed a need for a follow-up to the activity-pacing group to enable the



implementation of self-management strategies and maintain motivation for change. Some wanted to have more group sessions during the rehabilitation programme ‘to get deeper into the material.’ (Participant 3.) Others suggested meeting the same group a few months after rehabilitation: ‘because immediately after your rehab you’re so good, and then it fades. So, if you had a kick in the backside again, that might have helped.’ (Participant 9.)

Some participants clearly expressed a need for time to practise activity-pacing strategies in everyday life and then meet the group again:

*It’s all about first having awareness that this [fatigue] is a thing. And then you must live with it, to find solutions and ideas. Try, test; what works, what doesn’t, right? It takes time. (Participant 3.)*

Others emphasised the value of focussing on what they were able to manage and appreciating efforts to try their best, instead of focussing on what they felt they could not manage:

*So, I try to be a little more realistic, and be happy with what I can do. I think it’s important for everyone to be aware that they can actually do a lot themselves. Yes, I think a lot is about how we think. (Participant 6.)*

*I focus on what I can manage, instead of what I can’t. One thing I recognised was to give myself a pat on the back, because I can actually manage quite a lot, even if I feel like I can’t. (Participant 10.)*

After having practised and experienced how they were applying (or not applying) activity-pacing strategies, and how they perceived to manage their everyday life, some participants would meet the same group again. They valued the opportunity to share experiences and discuss how they had managed at home, as they expected to encounter barriers when trying to implement self-management strategies.

## Discussion

Our findings reveal that participants had been aware of their lack of knowledge of fatigue. They emphasised the value of meeting peers in the activity-pacing group led by an OT. Through discussions with peers and the OT, they acquired information and enhanced their understanding of fatigue and their motivation to self-manage. Despite using self-management strategies, most participants wanted a follow-up to the activity-pacing group; changing habits and implementing strategies takes time. Participants also wanted rheumatologists to pay more attention to fatigue and refer them to other health care professionals.

### *Participants’ experiences with an activity-pacing group*

Previous research found that fatigue is difficult to manage on one’s own [7,20], as it is perceived as unpredictable and inexplicable. The severe impact of fatigue on everyday life together with feelings of frustration and despair may result in even more fatigue [7]. This is in line with our findings, as the participants emphasise the need to understand fatigue in order to be able to improve the management of their daily activities. Thus, a lack of understanding of fatigue may help explain why people with IRDs struggle to manage their everyday activities. This indicates the need for information and support from health professionals [7,18]. It is recommended that the impact of fatigue on a person’s everyday life is addressed, that perceived challenges are discussed, and their efforts to enhance management by changing habits and using various strategies are supported [7,20,34]. An enhanced understanding of fatigue, together with support from health professionals, may help empower patients with fatigue in their efforts to self-manage everyday life, as they will have a better understanding of how to address the implications of fatigue.

In agreement with previous research [23], discussions with peers were valued by our participants, as was the presence of an OT to lead the group. The group setting facilitated the sharing of relevant knowledge and focussed discussions. This seemed to enhance the participants’ understanding of fatigue and increased their awareness that they themselves can do something to increase their management of everyday life. Their motivation to make these changes also seemed to have increased. This suggests that rather than simply receiving information on fatigue and management strategies from health professionals, group interventions may be useful for people with IRDs and fatigue.

### *Self-management of everyday life after group attendance*

Whilst our participants were positive regarding the activity-pacing group and the focus on fatigue and management strategies, most participants still perceived fatigue-related challenges at the time of the interview. A few participants reported managing everyday life better, despite having the same perception of fatigue as before group attendance. This may relate to those participants’ abilities to focus on achieving an increased level of activities by implementing activity-pacing strategies, rather than trying

to avoid fatigue as a symptom. Others may have applied activity-pacing strategies in order to reduce their perception of fatigue, which is not the goal of activity-pacing [21,25]. In line with previous research on activity-pacing and chronic pain [35], our findings imply that it may take time to change previous habits and to integrate the use of activity-pacing strategies into one's everyday life, as well as accept living with fatigue. Perceived social support may also be necessary to enhance such changes and acceptance of fatigue, as the implementation of activity-pacing strategies is assumed to be influenced by the context in which strategies are implemented [35].

Our participants prioritised activities perceived as meaningful and important. This is related to the goals and strategies of activity-pacing [25]. Participation in work was prioritised, as observed in previous research [7]. Maintaining roles and engagement in meaningful activities are important for a person's identity and well-being [36]. This might explain the challenges that our participants associated with changing habits and maintaining valued roles. Fulfilling valued roles is important even if it means that participants suffer the consequences of being unable to balance their energy use. As found for persons with chronic pain [35], an important aspect to the implementation of activity-pacing strategies is the negotiation in terms of which activities are to be prioritised and the need for possible changes regarding one's responsibility to carry out certain activities. Our findings indicate a desire to contribute to society and maintain social relations, which may be considered as a need to belong and to do something perceived as meaningful for oneself [36,37]. This may help explain why people with IRDs and fatigue often prioritise work, despite having less energy for other meaningful activities. Thus, supporting people with IRDs and fatigue to prioritise meaningful activities or make changes in order to fulfil valued roles, seems to be an important consideration for health professionals advising on self-management of everyday life.

### ***Reflections on unmet needs that may enhance self-management of everyday life with fatigue***

Our findings indicate a need for a follow-up of the activity pacing group. This may reflect that adapting to new situations and accepting fatigue is a continuous process [20]. Some participants asked for more group sessions throughout the rehabilitation programme, whilst others preferred practising activity-pacing strategies on their own before attending another group session. As our participants live in a

large geographical area, it may be challenging to attend group sessions at the hospital after the rehabilitation programme. Follow-up sessions in the participants' municipalities may therefore be an alternative. Previous research [38,39] indicates that, with respect to the impact of fatigue on everyday life, people with a range of chronic conditions have similar experiences like those described by the participants in our study. We, therefore, recommend that the municipal health service provides group interventions for people with fatigue and various chronic conditions, that target participants' individual needs [25,39]. Another alternative is to have follow-up sessions using digital solutions, such as video conferences, organised and led by, for instance, OTs at the hospital. In this way, the participants can remain in the same group as during their rehabilitation programme. The importance of this was stressed by our participants. It may be easier to share experiences and reflections with people they already know. However, more research is needed on the effectiveness of activity-pacing on self-management of everyday life for those with IRDs, and on participants' experiences of attending activity-pacing groups for people with various chronic conditions and fatigue [23,24].

Furthermore, regardless of how long the participants had been experiencing fatigue or whether they had informed health professionals about fatigue-related challenges, they expressed a lack of knowledge about fatigue before attending the activity-pacing group. Previous research highlights that fatigue is ignored and not adequately addressed by health professionals or rheumatologists [7,20]. Thus, in line with our findings, this indicates a need for rheumatologists to be more aware of a patient's need for information and support, by referring them to health professionals, such as OTs, who work with fatigue management. According to EULAR recommendations for the implementation of self-management strategies [19] and for the management of early arthritis [40], shared decision (i.e. communication, knowledge exchange, and achieving consensus regarding treatment decision) is an overarching principle within rheumatology care. Thus, paying attention to the patients' needs and referring them to relevant health care professionals should be an aim. The shared decision may help empower the patients to take an active role in their treatment and management of their disease and its impact on everyday life [19]. Being interested in a person's meaningful activities and roles is in line with the fundamental orientation of occupational therapy [36,37,41]. Furthermore, this is in

agreement with our participants' reflections on the importance of health professionals not simply focusing on their illness, but seeing them as an individual and acknowledging their story and feelings.

### **Methodological considerations**

The trustworthiness of this study will be discussed in regards to credibility and transferability. In terms of credibility, investigator triangulation, prolonged engagement, and persistent observation were applied [42]. Investigator triangulation was carried out by involving researchers with different occupational backgrounds (i.e. occupational therapists, rheumatologists, patient research partners). Still, other researchers could have emphasised different perspectives and research topics than we did. As the first author undertook the interviews, transcribed them and led the thematic analysis, biases may have arisen. The interview guide comprised several open questions regarding the topics of interest, emphasising the participants' elaboration of the questions. Furthermore, follow-up questions were asked to ensure that the participants' reflections and meanings were understood by the interviewer. This is considered strength of this study, in terms of enhancing its' credibility [42]. To strengthen the credibility of the analyses, the first author re-read and re-coded the data several times. The last author was involved in the analyses, as she coded three of the transcripts and discussed the meaning of the data and the codes with the first author. At a later stage, the analyses were discussed with all authors, including two patient research partners, and then refined. Member check was not conducted although such feedback from the participants could have further increased the credibility of our findings.

Regarding the transferability of the findings, we have provided thick descriptions of the context in which the intervention is carried out, of the research process, and our findings. Our sample includes both men and women, with a variation in age and work status, enabling the experiences and reflections of both genders and several age groups to be captured. Although our sample comprises more women, this represents the distribution of men and women attending the activity-pacing group. In this intervention, we focus on participants' activity performance, rather than avoidance of symptoms or activity. Therapists with knowledge of fatigue, the impact of fatigue on everyday life, cognitive behavioural therapy, and experience with group interventions and supervision,

should be able to conduct such interventions in different settings, including primary health care.

### **Conclusion**

Our findings indicate that it is important to enhance a patient's understanding of fatigue and to suggest ways to manage everyday life with fatigue. Group sessions focussing on activity-pacing (for those with IRDs) led by OTs may be a suitable approach to enhance patients' understanding of fatigue and improve their management of meaningful daily activities. However, the results indicate that implementing self-management strategies requires time. Most participants wanted a follow-up to the activity-pacing group, either during or after the rehabilitation programme, in order to enable them to make changes to their everyday lives by using various strategies.

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