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Let's talk about pain, the new important domain to assess and address in adult myositis—a qualitative study: a MIHRA collaboration

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Abstract

Objectives: Pain is a critical symptom to assess in clinical care and trials. This study aimed to explore experiences of pain in adults with myositis.

Methods: Patients were strategically identified to represent different myositis-diagnosis, duration and self-reported pain. Ten adults with polymyositis ($n=5$), dermatomyositis ($n=3$) or antisynthetase syndrome ($n=2$), six women, age range 28–71 years, median VAS pain score 59 mm (range 30–84 mm), participated in an individual, semi-structured interview. Interviews were audiotaped, transcribed and analysed by inductive qualitative content analysis.

Results: Three overarching themes emerged. The first was: 'Myositis pain—a new experience'. Myositis-related pain is unique and heterogeneous as to character, localization and duration. It can be chronic and fluctuate depending on disease activity. Adapted exercise and medical treatment can reduce pain. Activity balance and various coping strategies are keys to manage daily activities and pain. The second theme was: 'Pain impacts my life and my significant others'. Myositis-related pain impact self-perception and roles in life with additional impact on family and friends. They expressed frustration and sadness about others' inability to understand their pain. The third theme was: 'Education and support are key'. Participants emphasized the importance of knowledgeable health care providers to reduce the misinformation that myositis is a painless disease.

Conclusions: Pain is a key symptom of myositis, impacting many aspects of daily life and varies in character, location and duration. Although pain can be treated, it may persist as a chronic symptom, often worsening during flares. Health-care professionals should recognize and address myositis-related pain early and consistently throughout the disease course.

Keywords: idiopathic inflammatory myopathies, myositis, pain experience, patients' experience, qualitative.

Rheumatology key messages

- Myositis-related pain affects all parts of life and should be addressed through the disease course.
- Adapted exercise, coping strategies and medication can alleviate the pain and improve well-being.
- Knowledgeable healthcare providers and peer support is essential in managing myositis-related pain.

Introduction

Adult idiopathic inflammatory myopathies (IIM) are a rare group of autoimmune, systemic inflammatory conditions divided into subsets of polymyositis (PM), dermatomyositis (DM) [1] and inclusion body myositis (IBM) with additional classifications of antisynthetase syndrome (ASyS), immune-mediated necrotizing myopathy (IMNM) and overlap myositis [2–4]. Adult patients with non-IBM IIM experience reduced muscle endurance, muscle weakness and reduced aerobic capacity. In addition, patients are limited in daily activities and quality of life (QoL). Although most patients respond to the medical treatment of high-dose oral corticosteroids and other immunosuppressive agents with diminished inflammation and disease activity, most patients develop sustained physical limitations and reduced QoL [5, 6].

Historically IIM have been described as a 'painless weakness', and clinical care and research have focused mainly on examining and treating inflammation and muscle

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impairment. However, through qualitative research and consensus methodology, pain has emerged as one of the most important symptoms to assess in IIM, along with fatigue and physical function [7]. There has been an increasing interest in studying frequency and severity of pain in IIM. In a scoping review by Leclair *et al.*, 64–100% of patients with adult IIM reported pain with an intensity comparable to pain in other inflammatory rheumatic conditions, such as rheumatoid arthritis (RA) [8]. A recent study of self-reported pain in adult IIM in the USA indicated that 91.5% of 468 participants reported current or past pain and 99% of these individuals attributed their pain to myositis [9]. Further, pain is often elevated during a flare of IIM [10].

Although patients with IIM report similar frequency and levels of pain as in other rheumatic diseases, our understanding of the lived experience of pain in individuals with IIM is lacking. Therefor we aim to explore patients' experience of myositis-related pain by a qualitative approach.

Methods

Patients

Fifteen patients at the rheumatology clinic of Karolinska University hospital were invited to participate during 2017–2022. Three patients declined participation, one could not be reached within the study period, and one patient consented and completed the interview but was excluded due to self-describing as not having, or ever having had, pain as a myositis symptom. Thus, results are based on 10 interviews. Table 1 presents demographic data. The participants constituted a convenience sample and were strategically identified in the Swedish Rheumatology Quality register (SRQ) to represent patients of all adult ages, both genders, different IIM subsets, disease duration, and a variation of self-reported pain during the past 3 years. Inclusion criteria were definite or probable diagnosis of PM or DM according to EULAR/ACR criteria for IIM [1], ASyS according to Connor's criteria [2] or IMNM according to ENMC criteria [3], age 18 years and above, self-reported pain assessed by visual analogue scale (VAS) ≥30 mm at any time point during the last 3 years, and being able to speak and understand the Swedish language. Exclusion criteria were diagnosis of IBM, juvenile DM, overlap IIM, additional diagnosis of a widespread pain syndrome, concurrent other inflammatory rheumatic disease, or ongoing cancer.

Each patient was first contacted by letter including written information. Two weeks later, co-author M.T. contacted the patient by telephone to ask about verbal consent and answer any questions. Informed consents were obtained before each interview.

Interviews

The individual interviews were conducted at a location separate from the clinic. A semi-structured interview guide was used (Table 2). The guide was tested during the first interview, where the participant was asked to provide feedback on the questions, resulting in a minor revision. All interviews were audiotaped and transcribed verbatim by M.T., including notations of non-verbal expressions. The interviews lasted between 40 and 85 min.

Table 1. Descriptives data of the 10 informants with myositis at time of interview

	Median (range)
Diagnose subset, ASyS/PM/DM, *n*	3/5/2
Age, median (range), years	59 (28–71)
Gender, female/male, *n*	6/4
Disease duration, median (range) months	99 (7–360)
Corticosteroids, yes/no, *n*	7/3
Current corticosteroid dose, median (range), mg/day	5 (3.75–10.0)
DMARD, yes/no, *n*	9/1
PGA, median (range), VAS 0–100	10 (0–34)[c]
PtGA, median (range) VAS 0–100	55 (26–71)[c]
MMT-8, median (range) 0–80	74 (48–80)
HAQ, median (range), 0–3	1.13 (0.13–1.88)[c]
CK, median (range), microcat/l[a]	1.6 (0.8–11)
Extramuscular, median (range), VAS 0–10	5 (0–20)[c]
Pain, VAS, median (range), 0–100 mm	59 (30–84)[c]
Fatigue, median (range), VAS 0–100 mm	65 (14–92)[c]
ESR, median (range), (ref <20)	13 (1–33)[c]
CRP, median (range), (ref <3)	1 (0.5–27)
DAS-28, median (range), 0–28	0.4 (0–3.7)[d]
Time spent sitting, median (range), h/day[b]	4–6 (1–3 for whole day)[c]
Physical activity, median (range), h/week[b]	1.5–2.5 (0.5 to >5)[c]
Exercise, median (range), h/week[b]	1–1.5 (0 to >2)[c]
Working/retired/sick leave, *n*	6/4/0
Continent of origin, Africa/Europe/Middle East/North or South America, *n*	1/6/1/2

[a] Reference values: 0.7–4.7 males, 0.6–3.5 females.

[b] Physical activity was assessed by three questions in the Swedish Quality Registry with fixed response intervals, such as 4–6 h/day.

[c] One missing case.

[d] Two missing cases. ASyS: antisynthetase syndrome; CK: creatine phosphokinase; CRP: plasma C-reactive protein; DAS-28: Disease Activity Score, 28-joint count; DM: dermatomyositis; ESR: erythrocyte sedimentation rate; HAQ: Health Assessment Questionnaire; MMT-8: Manual muscle test, eight muscle groups; PGA: physician global assessment; PtGA: patient global assessment; PM: polymyositis.

Data analysis

Data were analysed using inductive latent content analysis to interpret the underlying meaning of the interviews [11]. This method distils spoken words from the interviews into fewer content-related categories that share a common meaning [12]. The analysis steps are detailed in Table 3. The process was iterative, moving between full interviews, condensed versions and codes to ensure data alignment. Examples of the analysis are shown in Table 4. Condensed versions and codes were triangulated among H.A., M.R. and H.P. until consensus was reached.

The study was approved by the regional ethical review board in Stockholm, registry number 2017/1697/31.

Results

Three overarching themes emerged: (i) 'Myositis pain—a new experience', (ii) 'Pain impacts my life and my significant others', and (iii) 'Education and support are key'.

Myositis pain—a new experience

The first theme, 'Myositis pain—a new experience', included two categories, 'Another type of pain' and 'Many factors influence my myositis-related pain'.

Another type of pain

Participants described that myositis-related pain is distinct from previously experienced pain, signalling that something

Table 2. Interview guide

	Main questions
Introduction	Are you experiencing pain related to your myositis? Please tell me about what troubles you the most in regard to your myositis diagnosis
Experience of pain	In what way is pain a trouble for you? Please try to be concrete in your description In what way does the pain bother you? Please tell me more about the pain characteristics, how the pain feels (e.g. pinching, throbbing …) In what part/s of the body do you feel pain? Please tell me if there is something that triggers the pain Is there something that worsens the pain, or is there anything that reduces the pain?
Duration	How long have you had pain? Has the pain changed during the time you have had myositis?
Reason for pain/explanatory model	What do you think the pain is caused by? Have you ever had an explanation as to why you have this pain? (Do you remember how you thought and felt when you got an explanation? If you didn't get an explanation, do you recall how you thought/felt then?)
Consequences/struggles in daily living	In what way are you hindered by pain in your life? Please give some concrete examples, e.g. is pain a barrier when exercising? Are there some activities that you wish to do, but are hindered by pain from performing? I'm thinking of the pain that you have described. Are others (family, friends, colleagues) affected by your situation? I'm thinking of the pain that you have described. Can you distinguish pain from other myositis-related symptoms? Is it pain that hinders you in your activities, or is it tiredness, muscle weakness or something else?
Coping strategies	What can you do to relieve/reduce the pain?
Communication	Have you spoken with others, like those close to you, about your pain? What were their reactions? If you could give any advice to someone else with myositis and substantial problems with pain, what would you highlight/emphasize?
Closing remarks	Do you think we have discussed what is considered important in regard to your experience of pain? Is there anything you would like to add?

Table 3. Description of the steps and actions in the analysis

Steps	Actions
Transcription	M.T. transcribed all interviews
Familiarization	All transcripts were meticulously read to get a sense of each participant's individual experiences of physical activity/exercises. The accuracy of the transcripts was checked by re-reading while the tape was played (M.T.). M.T. and H.A. read all transcripts
Condensation of meaning units	Meaning units, defined as words, phrases and sentences with common content related to the aim of the study, were identified in the transcripts. M.T. condensed all interviews into meaning units. All 10 transcripts were critically reviewed by H.A. and discussed with M.T. until a consensus was obtained
Coding	The process of condensing meaning units and coding was performed with minimal interpretation and in keeping with the words used by the participants. M.T. coded all the interviews and discussed them with H.A. until consensus
Sorting, grouping and labelling subcategories	Codes were grouped into subcategories by M.T. for all the interviews. All subcategories were reviewed by H.A. and discussed with M.T. until a consensus was obtained
Continued sorting into categories	All subcategories were grouped into preliminary categories based on a comparison of similarities and differences in a way that covered content while reducing the number of categories. This was done by H.A., H.P. and M.R. in an iterative way. The preliminary categories were peer-reviewed and discussed by all authors until consensus
Categories and themes	Main categories were further merged from the analysis by H.A., M.R. and H.P.

is wrong and that it is difficult to describe, and different from exercise-induced muscle soreness. Pain during flares is acute and contrasts with pain in more stable disease phases.

> *Myositis pain is a unique kind of pain that I feel in my thigh muscles and arms. I may not be able to explain it well, but I know it is different from any pain I have experienced before.* (Female–ID: 5)

Pain was described as the first and most severe symptom of the disease, followed by fatigue and then muscle weakness. However, participants also described that pain was not severe at first. Early pain was characterized as muscle ache and tingling in various parts of the body.

> *It all started with, I got a terrible ache in the arms, and I had so much pain in the shins and calves, those muscles were painful in the beginning, and then I got the skin rashes on my shoulders, my face and knuckles.* (Male–ID: 6)

Participants believed that their pain was caused by myositis, for example, muscle swelling can be a source of pain.

Table 4. Example of the analysis process

Meaning unit	Text condensation	Code	Subcategory	Main category	Theme
There is a difference, I can, I know that muscle soreness after exercise is different from the ache I experience with my myostis. (Male–ID: 3)	I can differentiate between muscle soreness and myositis-related pain	Difference in types of pain	Myositis-related pain is different	Another type of pain	Myositis pain—a new experience
In the beginning … in these parts, the thigh muscles and the calves, I was in terrible pain … like I wanted to cut the legs off. (Female–ID: 10)	Terrible pain in the beginning	Myositis started with pain	Pain was first symptom of myositis	Another type of pain	
I really need my micro-pauses, when I am not able to take a break, I overexert and get more pain. (Female–ID: 1)	Pauses important to avoid overexertion and pain	Resting is important	Activity balance is fundamental	Many factors influence my myositis-related pain	
When overexerting during exercise I get pain, like a severe ache in the muscles that I have exercised. (Male–ID: 3)	Overexertion during exercise cause pain	Overexertion cause pain	Physical overexertion is negative	Many factors influence my myositis-related pain	
If I don't do my range of motion exercises in the morning, I won't be able to cope with the pain during that day. (Male–ID: 8)				Many factors influence my myositis-related pain	

However, it was also mentioned that the cause of pain is uncertain.

> *I believe that the pain is caused by swelling. Like there is fluid accumulation in the muscles in my body, and then that it has something to do with the muscles, that they are weak and that maybe I overexert them.* (Female–ID: 1)

The character of pain was heterogeneous including dull, sharp, aching, burning, stabbing, pinching, acute, intense, radiating, stinging, cramping and inflammatory pain. It can affect the entire body, including muscles, joints and skin, and may occur both at rest and during activity. The pain can be constant as well as varying from hour to hour, day to day, or over time.

> *The pain is like, I would describe my current pain as a dull ache in my arms and legs.* (Female–ID: 4)

Many factors influence my myositis-related pain

All participants emphasized that adapted physical activity and exercise could help reduce pain. Exercise-induced muscle soreness was described as something positive, as it could help alleviate myositis-related pain.

> *With exercise, I think exercise can reduce the pain in my back, my calves and shins. Exercise, I believe that one must exercise and move one's body. I think that exercise is the key.* (Male–ID: 6)

Morning movement and stretching often led to a better day with less stiffness and pain, and medications, including paracetamol and ibuprofen, positively affected myositis-related pain and helped facilitate exercise.

> *Exercise can somewhat reduce pain, but I can't exercise without pain medication.* (Female–ID: 9)

At the time of diagnosis, a high dose of corticosteroids significantly reduced pain. However, as the corticosteroids were tapered, the pain resurfaced or increased.

> *My pain started in my hands and then spread all over my body, but then my pain disappeared with medication* [high-dose corticosteroids]. *Later, when my corticosteroid dose was tapered, pain resurfaced.* (Female–ID: 4)

Coping strategies were used to divert attention from the pain, such as engaging in meaningful and enjoyable activities and trying not to focus on the discomfort.

> *Engaging in enjoyable activities, like seeing my grandchildren and friends, relieves pain and helps me to think about other things. I'm doing something fun and don't think about the pain, this is challenging but very important.* (Male–ID: 7)

Activity balance was crucial, as it had the potential to reduce pain. Strategies included prioritizing tasks, planning, and taking breaks to rest between activities at work or in other contexts.

> *My colleagues are very understanding, they know everything about my disease, and they help me, we help each other. I just sit down and rest when I need and then I continue.* (Female–ID: 9)

Self-management strategies included soft massage, warm baths, healthy eating and weight control. Participants avoided carbohydrates to feel better and expressed that warm weather was beneficial, while cold or changing weather often worsened pain. Physical inactivity, like prolonged sitting or lack of exercise during a period of time, increased pain.

> *As long as I am outdoors, moving my body and getting my circulation going I feel less pain than after sitting still for an hour and then getting up, that's when pain is at its worst.* (Male–ID: 6)

Physical overexertion could also cause or increase pain, including severe muscle soreness and other types of pain typically unrelated to exercise. It was discussed that engaging in non-adapted exercise early in the disease course, before starting medical treatment, could worsen the pain.

> *Exercise can increase my pain if I start doing too much, like too soon … I have learnt to adapt and not do too much, and then I don't get so exhausted or have more pain.* (Male–ID: 6)

Fatigue and stress were also described as triggers that aggravated pain, and infection was also mentioned as a trigger of pain.

> *Exertion, when I get tired or stressed my pain worsens. It's got to do with my head … I'm not able to do something, my head says one thing and my body something else and I get angry with myself.* (Male–ID: 7)

Pain impacts my life and my significant others

The second theme, 'Pain impacts my life and my significant others', included two categories, 'Pain limits my life' and 'Pain impacts those around me'.

Pain limits my life

It was expressed that myositis-related pain negatively impacted the participants' self-perception and their roles in life. Feelings of sorrow, anger and frustration were expressed due to their inability to participate socially with family and loved ones.

> *I had feelings of shame for not being the mother I wanted to be.* (Female–ID: 10)

It was difficult to accept the impairments and limitations in life caused by pain, along with the fear of experiencing a relapse of severe pain, particularly during a disease flare.

> *I am afraid of not being able to move my body, movement is quality of life.* (Female–ID: 10)

Pain negatively impacted sleep, leading to increased fatigue, which in turn heightened the perceived pain, creating a downward vicious cycle. However, fatigue was also described as having a more significant impact on their lives than pain. Pain acted as a barrier to participation in daily and physical activities with family members, sometimes causing participants to avoid social engagements.

> *I think that fatigue is the dominant symptom for me, not the pain. I can take medication for my pain, and handle pain with exercise, but fatigue limits my life more.* (Male–ID: 8)
> *Very often, my pain is a hindrance for me to be active with my family.* (Male–ID: 3)

It was expressed that some activities were prioritized, even if they caused or worsened pain, because they were perceived as very meaningful.

> *I have two grandchildren who keep me active, and after taking care of and playing with them for a day, I have to rest the next day because then my pain is awful, but it's worth it, one just has to take it.* (Male–ID: 7)

Pain was reported to have a negative impact on sex and intimacy, including expressions of sadness because sex was no longer part of the relationship due to pain. There was a decreased sex drive as a side effect of corticosteroid treatment. Participants noted that being hugged by their partners caused pain. However, with an understanding partner, it was possible to regain sex and intimacy, though perhaps not in the same way as before the onset of myositis.

> *I would say it is tenderness in my body. So, when my husband comes … sometimes and wants to hug me, and he is very careful, and I say to him—don't hug me too tight cause that is not possible today.* (Female–ID: 2)

Work ability can be maintained with support from the employer; however, it was also reported that pain contributes to the need for sick leave and absence from work. Pain negatively impacted the ability to walk, particularly when climbing stairs. During a flare, pain could also impair balance.

> *I am more ill, with more sick-leave from work, I stay at home due to pain and inability to do anything.* (Female–ID: 9)

Pain impacts those around me

Participants expressed feelings of frustration and sadness that family members and others did not understand their pain experience and its impact on both physical and mental well-being. It was mentioned that it took a long time for family and friends to fully understand. Additionally, participants noted that others often could not see that they were in pain.

> *Well, my colleagues don't notice anything, they can't see my pain and it is frustrating … like I was faking to be allowed to be on my short-term sick-leave … they don't know how hard it's been for me. My family thinks that I am all healthy now because I can do most things, I'm active, but sometimes I am all drained of energy … I don't think that they understand, it's difficult for them to understand.* (Female–ID: 1)

Participants expressed a reluctance to show or talk about their pain with family or friends. Instead, they wanted to remain active despite the pain and be perceived as strong, resilient individuals who would not give up.

> *I don't want to sit at home and think about my disease, I want to go out and do something. So, if I'm in pain … it doesn't matter, I want to show that I am strong and go out and do stuff. Sometimes a thought pops into my head that I don't want to be dependent on a wheelchair.* (Female–ID: 9)

Participants mentioned that their families were very worried about their pain, particularly concerned that it would become a chronic symptom. Pain had a negative impact on mood, causing some participants to become irritable or grumpy towards family and loved ones, which they found very disturbing.

> *My mother was very worried about me (and the pain) in the beginning and went on sick leave in order to help me.* (Male–ID: 6)

Education and support are key

In the third theme 'Education and support are key', one category arose, 'Knowledge, information and support'.

Knowledge, information and support

The information participants received from their healthcare providers varied. For example, they were told that the pain they experienced could not be related to myositis, which led to worry and unnecessary suffering. The importance of healthcare providers being knowledgeable about the disease—particularly that pain can be a consequence of myositis—was emphasized. Conversely, information included that pain could indeed be part of the disease and that healthcare professionals could provide support and treatment.

> *I told the first physician that I met at the hospital that I had pain, but he told me that patients with polymyositis usually don't experience pain … I was shocked, I had so much pain that I really didn't notice my muscle weakness in the beginning.* (Female–ID: 4)

The importance of support from a dedicated, interprofessional healthcare team with expertise in myositis and a holistic approach was highlighted. Healthcare providers should be open and prepared to discuss sensitive topics such as sex and intimacy. Similarly, support from patient organizations and peers, both in real life and on social media, was emphasized.

It is essential to be able to talk about pain with family members and close friends, as this enables their understanding, acceptance and ability to provide support.

> *It feels good that people care about me.* (Female–ID: 1)
> *My partner and my best friend know everything about my pain.* (Female–ID: 4)

Discussion

This is to the best of our knowledge the first study to explore how individuals with myositis experience pain. Participants reported that their pain was directly linked to myositis and unlike anything they had previously felt. Pain may be the first symptom and varies in location and character. Adapted physical activity and exercise were seen as crucial for pain reduction, and medication is often essential to enable exercise. Various coping strategies were effective. Pain affected many aspects of life, including roles, relationships (intimacy and sex), social activities, work and emotions. Support from knowledgeable healthcare providers and peers was considered vital.

Pain was described as a new experience, and most participants believed it was caused by their myositis. Pain is considered, by both patients and healthcare providers, as one of the most important symptoms to assess in myositis [7], and a recent review reported that most patients experience pain [8]. The mechanisms behind pain in myositis remain unclear, but our findings from this small cohort indicate the presence of myositis-specific pain, which appears heterogeneous in location and character, often worsening during flares. This aligns with a study showing increased pain during flares in adult patients [10], underscoring the need for continuous pain assessment alongside myositis core set disease activity measures. Evaluating muscle function with the Functional Index 2 or 3 can also provide insight, as these tools allow patients to rate pain during testing [13, 14].

High-dose corticosteroids are commonly used to rapidly reduce inflammation in recent-onset, active IIM [15], and our results suggest they can also alleviate pain at disease onset and during flares. However, pain often returned as doses were tapered, highlighting the need for regular pain assessment using patient-reported outcome measures. The PROMIS Pain-Interference 6a is valid, reliable and sensitive to change in adult non-IBM IIM [16, 17]. Effective management requires addressing pain at all disease stages, not just inflammation. Alongside corticosteroids, NSAIDs and non-opioid medications play an important role in controlling pain and enabling physical activity. Pain management approaches differ globally; for example, opioid prescriptions are rare in northwestern Europe, whereas 69% of pain medication users in the USA reported prescribed opioid use [8].

Non-pharmacological interventions were seen as essential for optimizing quality of life. All participants reported that tailored exercise and physical activity, adapted to their fitness, fatigue and pain levels, helped reduce pain, consistent with studies in adult myositis, systemic sclerosis (SSc), and rheumatoid arthritis (RA) [8, 18–20]. Coping strategies such as pacing, distraction and staying socially active also eased the pain experience, echoing RA reports that daily activities both mediate and distract from pain [21]. Engaging in meaningful daily activities enhanced quality of life even when pain persisted. Maintaining activity balance requires the ability and resources to pursue meaningful activities [22]. Occupational therapists and physiotherapists play a key role in helping patients prioritize and sustain these activities.

Our results suggest that overexertion and stress can increase pain, consistent with reports from individuals with SSc who experienced severe muscle soreness after excessive exercise [20]. Conversely, physical inactivity may also worsen pain, underscoring the need for adapted exercise and activity balance. Pain affected emotional well-being and the ability to maintain life roles, with both participants and their families fearing that the pain will return, increase, or become unbearable. Similarly, in SSc, pain significantly impacts emotions and roles and is linked to reduced physical function and poorer health outcomes [23, 24].

Some participants found fatigue more limiting than pain, suggesting the two are interrelated; increasing pain may intensify fatigue. In RA, pain is a major contributor to fatigue [25], which may also apply to myositis. Both symptoms are linked to anxiety and depression in IIM [26], emphasizing the need to address psychological factors when evaluating pain, as also reported in RA [27].

Our findings highlight the value of healthcare providers specializing in myositis, who can deliver accurate information, guide pain management, and prescribe appropriate exercise and advice on activity balance. While multiprofessional specialist teams are common in Scandinavian rheumatology care, they are less prevalent worldwide. Networking with myositis specialists, such as through the Myositis International Health & Research Collaborative Alliance (MIHRA) (www.mihrafoundation.org) [28], is vital for optimal care. Participants also valued peer networking for information and support, with global collaboration between patient organizations and online groups serving as important resources for patients and families.

This study has limitations. Patients were recruited through convenience sampling to ensure diversity in myositis subsets, age, sex, disease duration and self-reported pain intensity. Although only 10 participants were included, data saturation was reached, suggesting further interviews would likely yield redundant data [29]. We were unable to include a participant with IMNM. None of the participants had a diagnosis of fibromyalgia or other generalized pain syndromes, though we cannot exclude the possibility that some may be at risk or already show signs. Our analysis followed established methodology, and triangulation enhanced the study's trustworthiness [11, 30].

In conclusion, myositis-related pain is a distinct experience that can precede other symptoms, is heterogeneous in nature, and may occur throughout the body with significant impact on patients and their families. Pain can be positively influenced by physical activity, exercise, medication, coping strategies and activity balance. Continuous pain assessment with validated instruments and early intervention are essential to prevent generalized pain. Our findings highlight the need for collaborative research, such as through the MIHRA network, to advance understanding of its mechanisms, assessment and treatment.

Data availability

The data underlying this article are available in the article or available from the authors upon reasoned request.

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