

ORIGINAL ARTICLE

“A body in transformation”—An empirical phenomenological study about fear-avoidance beliefs towards physical activity among persons experiencing moderate-to-severe rheumatic pain

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Abstract

Aims and objectives: To gain a better understanding of fear-avoidance beliefs towards physical activity and body awareness in people experiencing moderate-to-severe rheumatic pain.

Background: Rheumatoid arthritis and psoriatic arthritis are long-term conditions with pain as the prominent symptom. Health-promoting physical activity is recommended and can have an analgesic effect. High self-rated pain has previously been reported to be associated with increased fear-avoidance behaviour in relation to physical activity. Body awareness, which includes attentional focus and awareness of internal body sensations, could be valuable in the nursing care of long-term diseases.

Design: Empirical phenomenological.

Methods: An empirical phenomenological psychological method was applied. The interviews took place between autumn 2016–spring 2017 with 11 informants (eight women and three men, age range 44–71 years) who were diagnosed with rheumatoid arthritis ($n = 7$) or psoriatic arthritis ($n = 4$), with a disease duration ranging from 3–35 years. The mean visual analogue scale score in the study sample was 60 mm.

Results: Three typologies were identified: “My relatively fragile physical status”, “I am an active creator” and “Part of something bigger than myself.”

Conclusions: The current findings indicated that pain anticipation and fear-avoidance beliefs towards physical activity sometimes affected the behaviour of individuals with long-term rheumatic pain syndromes. People experiencing moderate-to-severe rheumatic pain tended to focus on their fragile physical and emotional state. By adopting a more favourable attitude towards the self, the body could be restored to a state of calm and balance.

Relevance to clinical practice: The current findings are relevant for healthcare professionals engaged in health-promotion clinical practice.

KEYWORDS

body awareness, fear-avoidance beliefs, health-enhancing physical activity, pain, rheumatic diseases

1 | INTRODUCTION

Rheumatoid arthritis (RA) and psoriatic arthritis (PsA) are inflammatory diseases characterised by chronic arthritis that can result in considerable disease burden. Disease activity and symptoms of RA and PsA can contribute to reduced physical, emotional or psychosocial health and well-being (Engbrecht, Kruckow, Araujo, Rech, & Schett, 2013; Lee, Mendelsohn, & Sarnes, 2010; Myers, Gottlieb, & Mease, 2006; Perrot, Dieudé, Pérocheau, & Allanore, 2013; Sharpe, 2016). A physically active lifestyle is associated with reduced risk of several diseases, including cardiovascular disease (CVD), type 2 diabetes and osteoporosis (Swedish Council on Health Technology Assessment, 2007). However, only a minority of people with RA participate in health-promoting physical activities (Demmelmaier, Bergman, Nordgren, Jensen, & Opava, 2013). In addition, people with RA report high levels of pain-catastrophising (Lee et al., 2014) exhibited as high levels of self-rated pain associated with increased fear-avoidance behaviour towards physical activity (Löf et al., 2015). A negatively toned body awareness occurs when attention is primarily focused on the rheumatic pain and symptomatic body (Löf, Johansson, Welin Henriksson, Lindblad, & Bullington, 2014). This study was conducted to gain better insight into fear-avoidance beliefs in relation to physical activity among people experiencing moderate-to-severe rheumatic pain.

2 | BACKGROUND

Rheumatoid arthritis and PsA are characterised by tenderness, stiffness and joint pain. However, people with PsA are typically affected with psoriasis before joint disease has developed. Pain and fatigue are described as crucial outcome measures in people with RA and PsA (Carneiro et al., 2017; Garrido-Cumbrera et al., 2017; Hochberg, Silman, Smolen, Weinblatt, & Weisman, 2011; Kilic, Erden, Bingham, Gossec, & Kalyoncu, 2016; Lee et al., 2014; Myers et al., 2006; Verstappen, 2013; Walsh & McWilliam, 2014). Patients with RA and PsA face an increased risk of developing CVD (Agca et al., 2016). In some cases, the disease course is short and limited, while other cases emerge as progressive diseases that lead to physical disability (Eurenius & Stenström, 2005; Lee et al., 2010).

Pain can be defined as an unpleasant sensory and emotional experience that is associated with actual or potential tissue damage (International Association for the Study of Pain, 2017). According to Walsh and McWilliam (2014), rheumatic pain can be constant or intermittent, and localised or spread out. People experiencing moderate-to-severe rheumatic are often examined as patients in clinical practice (Taylor et al., 2010). Long-term pain has been explained using various models involving different underlying mechanisms (Bas, Su, Wigerblad, & Svensson, 2016), such as the relationship between pain, fatigue and mood in people with RA who experience long-term pain (Feldthusen, Björk, Forsblad-d'Elia, & Mannerkorpi, 2013; Walsh & McWilliam, 2014). Ahlstrand, Björk, Thyberg, Börsbo, and Falkmer (2012) reported that long-term pain is a prominent complaint leading to reduced work

What does this study contribute to the wider global clinical community?

- Both adaptive and maladaptive body awareness should be more carefully addressed in the care of people experiencing moderate-to-severe rheumatic pain.
- The healthcare system needs to address people experiencing high-fear-avoidance behaviour in relation to the individuals' own descriptions and lived experience.
- This paper provides insight into fear-avoidance beliefs in relation to physical activity in people with moderate-to-severe rheumatic pain.

ability in people with RA (Ahlstrand et al., 2012). Improving physical and social functioning, as well as work productivity, is considered an important treatment goal in people with PsA (Garrido-Cumbrera et al., 2017). Being unable to participate in physical activities in daily life has been found to cause negative emotions, adversely affecting the well-being of people with RA who suffer from long-term pain (Östlund et al., 2014). Health-promoting physical activity is recommended for people with long-term illness (Nelson et al., 2007). Treatment goals for RA and PsA include the following: reducing mortality, relieving/reducing pain and preventing loss of physical function. Appropriately designed exercise is known to have an analgesic effect (The National Board of Health and Welfare, 2012). To reduce the risk of aggravated disease symptoms relative to increased physical activity in people with rheumatic diseases, Swärdh and Brodin (2016) highlight the importance of professional support and the need to develop and implement an individualised physical activity plan. The researchers note that exercise should start at a low level and gradually increase as tolerated (Swärdh & Brodin, 2016).

Vlaeyen and Linton (2000) presented an overview of the evidence demonstrating that, in the case of long-term musculoskeletal pain, avoidance is typically focused on avoiding a perceived threat (fear-avoidance), such as physical activities that are assumed to increase pain. Evidence also indicates that pain-related fear is related to catastrophic misinterpretations of pain and amplified escape and avoidance behaviour that often generates intensified pain and increased functional disability (Vlaeyen & Linton, 2000). Perrot et al. (2013) observed that pain-catastrophising (the process by which pain is experienced as extremely threatening) plays an important role in understanding the experience of long-term pain. Ginzburg et al. (2015) reported that when an individual's pain orientation is highly catastrophic, they often also have high levels of body awareness. Body awareness is a multifaceted phenomenon, and a clear definition has yet to emerge. Mehlhing et al. (2009) attempted to define body awareness using four domains: perceived body sensations, quality of attention, attitude of body awareness and awareness of mind-body integration in defining body awareness. The researchers proposed that the perceived body sensations domain (which includes attentional focus on and awareness of internal body sensations) could be useful in the treatment of long-

term pain (Mehling et al., 2005, 2009). In addition, it has been suggested that this domain may be helpful for evaluating a person's body awareness in the management of long-term illness and could be addressed in a nursing context (Löof, Johansson, Welin Henriksson, Lindblad, & Saboonchi, 2013). Previous studies have also reported unilateral body awareness in people with RA. Negatively toned body awareness occurs when attention is primarily on the symptomatic (painful) body (Löof et al., 2014).

3 | AIM

To gain a better understanding of fear-avoidance beliefs towards physical activity and body awareness in people experiencing moderate-to-severe rheumatic pain.

4 | METHODS

4.1 | Phenomenology

Phenomenology is the study of phenomena based on an informant's description of their lived experience (Husserl, 1962). Phenomenological methods focus on the meaning and significance of experiences among humans from a so-called life-world perspective. The life-world is inseparably connected to the subject that experiences it and lives in it. Because the description comes from a first-person point of view, substantial and varied data can be collected (Husserl, 1962; Spiegelberg, 1982). In this study, we used the empirical phenomenological psychological (EPP) method (Karlsson, 1993), seeking to determine the essence and constituents of participants' experience. In this type of methodology, researchers must be open to phenomena as they are presented. Thus, researchers must contain and reflect their preconceptions, to allow possible new meanings to emerge from the data (Bayne & Montague, 2011).

4.2 | Informants and data collection

We employed purposive sampling to select informants who shared certain characteristics. The aim was to provide a heterogeneous group. We included informants who were aged between 20–100 years, with a confirmed diagnosis of RA according to the American College of Rheumatology classification criteria (Aletaha et al., 2010; Arnett et al., 1988) or PsA according to the CASPAR (classification criteria for psoriatic arthritis) classification criteria (Taylor et al., 2006), and a disease duration of at least 6 months. The selection criteria were designed to include individuals with moderate (>30–60 mm)-to-severe (>60–100 mm) levels of rheumatic pain. Individuals with an estimated pain level of >30 mm on the visual analogue scale (VAS) (Huskisson, 1982) over the past week were included. Informants with major linguistic difficulties or those with other diagnosed diseases that included a major pain problem were excluded from the study.

Healthcare professionals at a hospital in Sweden recruited informants meeting the inclusion criteria from patients visiting the

rheumatology clinic. Information was given to the informants by the healthcare professional. Informants who expressed interest in participating were asked to add their name to a list, and to provide a current mobile phone number. Based on this list, the first author was notified of the informants' names and phone numbers, and subsequently telephoned them. During the telephone conversation, informants were offered additional information. Finally, they were asked for their verbal consent to participate. Thirteen informants were selected and asked to participate. One informant cancelled the interview because of stressful life circumstances, and another could not be contacted. Thus, the final sample comprised 11 informants (eight women and three men, age range 44–71 years) with a disease duration ranging from 3–35 years, who were diagnosed with RA ($n = 7$) or PsA ($n = 4$). During the week before the interview, informants were administered a self-report VAS measuring rheumatic pain. The VAS-scale ranged from no pain at all (0 mm), to the worst pain imaginable (100 mm). The mean VAS score in the study sample was 60 mm.

The first author, with detailed knowledge of the EPP method, conducted all of the interviews. Only the informant and the interviewer were present during the interviews. The audio-taped interviews, lasting an average of 75 min, took place in a private area of the rheumatology clinic at the hospital. The interviews took place between autumn 2016–spring 2017. The interviewer was not involved in the informants' care or treatment.

4.3 | Preliminary study

A semi-structured interview guide with open-ended questions was used (see Appendix). The questions were used to stimulate narratives. The narrative interview sampling method was designed to achieve representation of the diversity of lived experiences of the phenomenon. The interview guide was initially tested to determine whether it was possible to address the questions (preliminary study) according to Aspers (2009) among both healthcare professionals ($n = 2$) and informants ($n = 2$), and was confirmed to have a high level of usefulness. No questions were revised.

4.4 | Data analysis

The 11 audio-taped interviews were transcribed verbatim by the first author and validated by the second author. We performed analysis in five steps, in accord with the method proposed by Karlsson (1993). First, a reading was performed to achieve an initial understanding of the text. The first author read all of the entire transcribed interviews and separately listened several times to the tape recordings of each informant. Next, interview texts were divided into meaning units. This process was performed by marking where a change in meaning occurred in the text. The meaning units were transformed into the researcher's language. The focus was on the significance of the meaning, in relation to the aim of the study. Later, the transformed meaningful units were gathered as individual structures, to form a synopsis. One structure was produced for each individual interview. Finally, the condensed structures were synthesised into general characteristics

(common to all 11 narrative accounts). Any variations of the phenomena were interpreted in terms of typological structures. The general characteristics were those constituents that were similar throughout all the narratives. In contrast, the variations (typologies) described the different ways in which the phenomena appeared. The aim of this process was to grasp the way the informant understood and related to the phenomena.

5 | ETHICAL CONSIDERATION

Ethical approval was obtained from the ethics committee of the Regional Ethical Review Board (Dr.nr. 2016/1236-31/4). Because patients with moderate-to-severe rheumatic pain were included, informants were asked if they needed a break during the interview. Two informants required a break due to pain (approximately 10 min).

6 | FINDINGS

6.1 | General characteristics

There were general characteristics common to all narrative accounts. This domain had to do with experiencing a body in transformation. The problematic body was made apparent by the difference in bodily strength, compared with before the rheumatic diagnosis was established.

Physical activities often had to be planned long in advance. Furthermore, physical activities were sometimes cancelled because of disease exacerbation. Participating in physical activities also demanded a long recovery period because of increased bodily pain or intense soreness occurring days after the physical activity. However, the informants felt that physical activities were highly important for their general health and well-being. Being unable to participate unhampered in everyday physical activities led to feelings of confinement and isolation, often accompanied by a persistent feeling of helplessness. The problematic body was also characterised by a cycle of fear-avoidance belief, and fear of social disconnection. The fear of suffering increased rheumatic pain, or other disease-related symptoms, as well as leading to decreased physical activity and reduced social interaction. The lack of social involvement further discouraged the individual from actively engaging in physical activity, adding to the complications of problematic body. During periods of solitude or sedentary activity, inner bodily attention could be directed unhindered towards the problematic body. Involvement in a wider social context, and professional support to discover new and creative solutions for daily physical activities, was reported to alter individuals' feelings of hope and inner strength and gaining access to a trustworthy body. By adopting a more favourable attitude towards the self, the body could be restored to a state of calm and balance. However, differences in the interview descriptions revealed the following three typologies: "My relatively fragile physical status," "I am an active creator" and "Part of something bigger than myself." Each typology was exemplified by the informants' descriptions.

6.2 | Typology 1

6.2.1 | My relatively fragile physical status

In this typology, informants' focused their attention on their relatively fragile physical status, which hindered their participation in daily physical activities. The informants' uncomfortable body and unpredictable bodily signals were the main subject of their attention and concern. Informants felt that it was very difficult to cope and find new adaptive strategies to live a physically active life. Comparisons with the unproblematic body appeared in this typology, which created negative emotional states, including feelings of sadness, anger, frustration and hopelessness:

It's very boring! It's not such a life as I had before, before I became ill with rheumatism. Before, I did everything in life! (Informant 3)

Because of the daily pain and stiffness caused by rheumatic disease, informants reported that the body could not be trusted to perform daily physical activities. Such severe pain often hindered participation in most physical activities. The informants reported that they felt different to other people because of their condition. In this typology, informants expressed having problems with fatigue, and that their bodies lacked energy and balance. Fear-avoidance beliefs towards physical activities were sometimes acknowledged. This presence was largely due to the fear of increased pain during or after physical activity:

Yes, I certainly avoid some situations because of the fear of increased pain. Yes, definitely! For a while, I sat on a chair at home, you know, all day long because I had so much pain! (Informant 7)

Moreover, informants in this typology reported a fear of mistrusting their energy levels and physical capacity, and a fear of not being able to cope with their own bodily signals during physical activities. By taking an inventory of physical abilities, activities had to be prioritised and planned a long time in advance. Informants in this typology saved energy and only participated in very special or highly important activities, which could be viewed as an active and reflective choice:

If I do something one day, I always have to consider my energy level. I always take it extremely easy afterwards, remaining sedentary for several days. Is the physical activity really worth it? (Informant 11)

A further issue for informants in this typology was the fear of spending too much time alone. They noted that during long periods of solitude or sedentary activity, they would begin to have excessively negative thoughts. Consequently, inner bodily attention could be directed unhindered towards the inner bodily signals.

However, the informants had detailed knowledge about the health benefits of being physically active, and often contemplated the disadvantages of being physically inactive. They longed to live a life in which they were healthier and more physically active. Despite this knowledge, they pointed out the many obstacles to physical activity, and expressed a strong distrust for future activity plans. The feeling of having a malfunctioning body that they mistrusted overshadowed their cognitive and emotional attention:

Because I can no longer live like a normal person, if I say so. I think this is problematic. Yes, it is there all the time in the back of my head! Yes, now the body is problematic. I cannot participate in the things other people do. (Informant 1)

The informants also conveyed that this type of choice made life more complicated and more sorrowful because it interfered in maintaining old social or work relationships. Moreover, informants' conditions were not always understood or welcomed among relatives or in the workplace. This situation sometimes produced thoughts of fear for isolation and despair. Informants also pondered over the fear of being a burden to their relatives or others. Being as independent as possible was viewed as an ultimate goal. They felt that their malfunctioning bodies stood in the way of living a normal life. Because of changing life circumstances, informants felt that their lives became vulnerable, uninfluential and even out of control. Being physically unable to perform a job, or having to take sick-leave or early retirement due to sickness, tended to create feelings of inferiority and disconnection from society.

6.3 | Typology 2

6.3.1 | I am an active creator

Informants in this typology expressed that their body needed physical activity, and, importantly, they felt they were still capable of carrying out physical activities. Informants felt that it was important to visibly demonstrate that their body was functioning. They often mentioned their willingness to take part in physical activities, and their inner strength. A hopeful attitude and a spirit towards engaging in activities in daily life were apparent. Informants mainly focused on the active self and the capable body. Maintenance of physical activities was experienced as an important element for improved health and well-being. Because physical activities were experienced, a comfortable body and a positive and focused mind were experienced:

If I see the slightest chance to make it, then I do it, try it! I have, in the past, avoided certain situations, although I do not think of that (history) anymore! Instead, I reflect on now and on the good things, the things that actually are here! (Informant 5)

The emphasis in this typology was that long-term rheumatic pain would seldom stop them from performing some form of physical

activity. Instead, being aware of and listening to their body signals helped the informants to understand the relationship between their physical symptoms and life experiences. Having active communication with oneself was another aspect of this typology. This meant that knowing one's limitations helped informants apply smart solutions to solve daily situations, such as taking it easy during flare-ups. The informants' solutions in daily life were often concerned with the planning of their physical recovery:

But there is nothing that stops me just because I have rheumatic pain! I just put in good periods of recovery! (Informant 8)

Increased body awareness meant understanding and listening to the vulnerability of the body in relation to pain and assault. Informants expressed the importance of taking care of their bodies on a daily basis, and to like and cherish their body as a close friend. Informants reported that awareness also meant not being so hard on themselves, and to reflect and learn to listen with curiosity and self-empathy. Furthermore, informants placed emphasis on continuously evaluating what worked well in everyday physical activities. They expressed the importance of developing individualised strategies that worked best for a specific situation, enabling them to stay engaged and active in life. There was a strong desire to continue to live a normal and physical active life, just like people in the general population. Informants also expressed a strong need to be taken seriously, and to be regarded as capable individuals. A person-centred approach was described as a very important component when the informants interacted with healthcare providers for support:

I'm a person. You should NOT consider me as the sick one. I'm like this because this is my body and my soul. I'm human. I'm not a disease. I'm a person! (Informant 9)

In this typology, informants reported that information about the health benefits of living an active life and applying adaptive strategies to remain physically active was obtained not only from healthcare professionals, but also from the informants themselves, who considered themselves active information seekers.

6.4 | Typology 3

6.4.1 | Part of something bigger than myself

In this typology, informants' descriptions were about seeing themselves in a wider social context, which was the main source of positive energy and self-efficacy. Informants expressed an acceptance of their physical condition. Furthermore, a curiosity in relation to the body in transformation was described, even when it entailed experiencing a changing and problematic body. The informants in this typology downplayed the focus towards the self and body

awareness. Informants noted that very little time was spent reflecting on inner bodily signals.

Informants reported that they focused on communicating and sharing experiences, and participated in various physical activities as often as possible. This mode of thinking meant that informants strove to play an active part in society. Through different social networks, such as paid or volunteer work, they described how their inner world became more meaningful and how the focus shifted from their own body and self to others', through the process of interaction. Interacting with other people often led to a sense of bodily calmness and tranquillity of mind. To belong to someone or something was important, in a context where the person could be physically active. This was also seen as a place to rest and recover:

I walk to the water, with a friend and we bring some coffee with us. The focus is on the silent moments, the nature, the animals, the water, you know...

(Informant 4)

Informants claimed it was easier to cope with pain when they focused on daily activities. They emphasised the importance of being an engaged individual. In addition, being given credibility within different social contexts was highly valued. Informants stated that the motive was to be a role model and to provide support to others. They interpreted this as leading to a meaningful and active life, which was considered necessary to maintain general health and well-being:

Situations in which I do not pay attention to my own body occur when I'm working. First, I work with a lot of people—hundreds of colleagues and thousands of customers. You must focus on what you do. One must have focus to produce. Therefore, I'm so afraid of retiring. I have seen so many people who grow older and how bad it has been when they retire. It scares me a bit. It actually does! They certainly have their worries and illnesses. It's possible, but terrible, how hard it (retirement) is on people. Yes, yes, yes it is!

(Informant 6)

In this typology, there was an overwhelming feeling of being alive, and being excited about life. Informants saw several benefits of their "new" life. Still, on several occasions, informants experienced considerable pain and sorrow, but could overcome these "dark" times and move forward. They interpreted their present life as a form of "existential awareness." For those in this typology, their challenging situation was a major life experience, and through the difficult times, there were significant gains in terms of the way life emotionally and existentially evolved:

So, music is a big interest that I have today. Then, I have thought about this, yes, the disease, not thanks to it, but because of it and life, I got these

opportunities. I would never have received these opportunities if I were still working. No, I worked forever. So, all this I have now. With buddies and culture and stuff. I would never have them otherwise. Never. So, I feel quite satisfied anyway. Actually, I do! (Informant 10)

During flare-ups, embracing professional help and social support were crucial. Support from the healthcare system was highly valued, as it provided expert knowledge and help in finding new strategies and tools to enhance daily living and quality of life. Informants felt that they had found viable alternative ways to help them to participate in physical activities.

7 | DISCUSSION

Three typologies appeared from this study: "My relatively fragile physical status", "I am an active creator" and "Part of something bigger than myself".

Maintaining a level of daily physical activity was regarded as a key element for general health and well-being. Garrido-Cumbrera et al. (2017) describe improving physical and social functioning, as well as work productivity, as important treatment goals in people with PsA. To reduce the risk of aggravated disease symptoms in connection with increased physical activity in people with rheumatic diseases, Swärdh and Brodin (2016) highlight the importance of support with an individual physical activity plan.

Pain-related fear is often described in people with musculoskeletal pain, and significant levels of self-rated pain are related to increased fear-avoidance behaviour towards physical activity (Löof et al., 2015). The present results also revealed that fear-avoidance beliefs towards physical activity sometimes arose because of a fear of increased rheumatic pain or other disease-related symptoms, during or after physical activities. Several other fears were also mentioned. A mistrust of the body's energy levels and physical capacity, or having to live in solitude in a sedentary way, were all reported to lead to negative thoughts and emotions. Bodily attention could then be directed unhindered towards the uncomfortable body. Kirmayer and Looper (2006) proposed that a strong tendency towards awareness of perceived body sensations may lead individuals to dwell on different body functions. In some people, this may create somatisation and anxiety problems (Kirmayer & Looper, 2006).

Nygren Zotterman, Skär, Olsson, and Söderberg (2016) reported that patients with long-term illness described a strong need to be confirmed and met with respect by healthcare personnel, and that having a sense of togetherness strengthened patient well-being (Nygren Zotterman et al., 2016). Raising awareness of perceptions of fear-related phenomena in relation to physical activities, as a way of providing adaptive professional support with a nonjudgemental attitude, is important for people with long-term illness. In the current study, involvement in a wider social context and support to discover new and creative solutions to enable daily physical activities were

reported to alter individuals' feelings of hope and their inner strength (as well as their ability to gain access to a trustworthy body). Östlund et al. (2014) reported that their informants expressed sadness if they were unable to continue working. Similarly, the informants in the current study reported the need to be productive and contribute to society in a meaningful and active way. As in the present study, Lööf et al. (2014) reported that the capacity to shift attention from body awareness to activities in the outside world could be valuable to a person's general health and well-being.

The current findings revealed that physical activities were often planned a long time in advance. Furthermore, informants sometimes had to cancel activities because of flare-ups involving increased pain. Participating in physical activities was also found to demand a long recovery period. McCormark and McCann (2010) suggest that living with a long-term illness can create distance between what a person wants to manage and what a person can manage. The current findings highlight the need for a person-centred approach. According to McCormark and McCann (2010), a person's view about their life situation and condition should be at the centre of the care process in person-centred care. Such a view considers a person's narrative of their illness, their symptoms and the impact their symptoms have on their life. This approach is in line with recommendations of the International Council of Nurses (2012), which declare that healthcare professionals should adopt a holistic perspective. Östlund et al. (2014) also found that being unable to participate in daily physical activities may result in a range of negative emotions in people with long-term rheumatic pain. The current findings indicate that being unable to participate in everyday physical activities in an unhampered way led to isolation and helplessness. Consequently, addressing a person's negative feelings requires focusing on their self-efficacy (a person's belief in their own capacity to be successful in a specific situation). According to Bandura (1995), learning how to evaluate mood when facing demanding tasks is a source of increased self-efficacy. Both adaptive and maladaptive body awareness should be more carefully addressed in the care of people experiencing moderate-to-severe rheumatic pain.

7.1 | Limitations

This study involved several methodological limitations that should be addressed. Graneheim and Lundman (2004) argue that qualitative researchers should strive to achieve a high level of trustworthiness. Thus, notions of transferability, confirmability and dependability are discussed below.

The informants in the current study were, to some extent, comparable to the general Swedish population regarding the prevalence and incidence of RA (for example, RA is higher in women in both the general population and in our sample) (Eriksson et al., 2013). Only informants with moderate-to-severe rheumatic pain were included in the current study, because rheumatic pain was considered a key outcome measure (Carneiro et al., 2017; Garrido-Cumbrera et al., 2017; Lee et al., 2014; Walsh & McWilliam, 2014) and patients with RA who consider their disease to be somewhat or completely controlled continue to report moderate-to-severe pain

(Taylor et al., 2010). We only included informants from one geographical region in Sweden. In a qualitative study, such a limitation may affect the transferability of the results.

Because we sought to include diverse and rich narratives regarding the phenomena under investigation, a healthcare professional at the hospital manually selected the informants, including people who fulfilled the inclusion criteria and expressed an interest in participating in a narrative interview about the topic of interest. The interviews were conducted locally according to the informant's preferences, and the interview guide was tested (preliminary study) and found to provide a high level of usefulness (no questions were revised).

Karlsson's (1993) EPP method was used because we sought to focus on the informants' subjective, lived experiences of the phenomena under investigation. According to phenomenological approach, the consciousness one has of the experience is what makes an experience conscious (Husserl, 1962). However, the informants were not given an opportunity to give feedback on the findings because of practical limitations, which may have affected the confirmability of the current results. Based on the EPP method (Karlsson, 1993), the authors worked to reach a consensus regarding the findings, via meetings, reflections and discussions over a longer time period (during 2016–2017). The authors' preconceptions were also discussed during the study. The first author had detailed experience in qualitative analysis and extensive knowledge of the phenomena under investigation, which may have affected the reliability of the current results. However, the researchers discussed the data together, and agreed on the final results. It is ultimately the reader who must assess the trustworthiness of the current findings (Graneheim & Lundman, 2004).

8 | CONCLUSIONS

The current findings indicated that pain anticipation and fear-avoidance beliefs towards physical activity sometimes affected the behaviour of individuals with long-term rheumatic pain syndromes. People experiencing moderate-to-severe rheumatic pain tended to focus on their fragile physical and emotional state. By adopting a more favourable attitude towards the self, the body could be restored to a state of calm and balance.

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CONTRIBUTIONS

Study design: HL; data collection: HL; analysis: HL, UBJ and manuscript preparation: HL, UBJ.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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APPENDIX

- Can you tell me about your rheumatic pain?
- Can you tell me how much pain (VAS) you have had during the past week due to your rheumatic disease?
- Are there certain physical activities or situations that you avoid for a fear of an increased rheumatic pain? If yes:—Can you tell me about this fear?—Can you tell me about in what ways you relate to this fear of increased rheumatic pain in your everyday life?
- Can you tell me about a physical activity or a situation when you notice the body as very disturbing (painful)?
- Can you tell me about a physical activity or a situation when you notice the body as very comfortable (without pain)?
- Are there situations or physical activities when you do not notice your own body? (If yes:—Can you tell me about it?).