

Inhabiting one's body or being haunted by it: a first-person study of the recovery process of women with fibromyalgia

Abstract

Objective: The aim of the present study was to explore the bodily experience of fibromyalgia patients' recovery process, focusing on the changes that, from the patients' perspective, were significant in the progression towards health.

Methods: Eight women who had recovered from fibromyalgia participated in the study. Data was gathered and analyzed using qualitative, phenomenological and arts-based methods, combining different levels of description: a narrative level using semi-structured interviews; an embodied level using the micro-phenomenological interview and body mapping, and a non-verbal level also provided by the body mapping method.

Results: Four overarching themes were identified from the qualitative data collected from the semi-structured interviews. These themes outlined a process of sense-making that transformed the relationship participants had with their symptoms and with themselves. The micro-phenomenological interview allowed identification of the micro-dynamics of specific moments of new understanding within the recovery process, demonstrating that getting in touch with bodily sensations, whether pleasant, unpleasant or neutral, by becoming aware of them and pondering or relaxing into them, allows for changes that appear crucial to the recovery process. The body map enabled us to include a pre-reflective, sensorial and non-verbal level of description that complemented the analysis of the micro-phenomenological interview. The maps portrayed two bodies: one representing the state of the participant before the new understanding and the other the state after it. The two bodies contrasted in various aspects, such as shape, color, posture, as well as the associated feelings these images produced. In addition to the contrasting aspects of the two silhouettes present in the body maps, common elements were identified indicating that in the process of change, the patients also recognized a unity or continuity, something that was already present in them and that somehow allowed such change.

Conclusions: Our results are consistent with the idea that recovery involves a process of sense-making of what is experienced. More importantly, our results showed that a cornerstone of the sense-making process is gaining familiarity with bodily self-awareness. The integration of the three methods used allowed us to approach different aspects of the participants' subjective experience, deepening the understanding of the fibromyalgia recovery process and contributing to the discussion of the place of subjective experience in scientific research.

Keywords: fibromyalgia, first-person research, body-awareness, recovery process, change process, experience research, embodiment

Camila

Valenzuela-Moguillansky¹²

Daniela Díaz¹

Alejandra

Vásquez-Rosati^{1,3,4}

Javiera Duarte^{5,6}

1 Centro de Estudios

Laboratorio de
Fenomenología Corporal,
Villarrica, Chile

2 Facultad de Psicología,
Universidad Diego Portales,
Santiago, Chile

3 Laboratorio de
Neurofisiología Cognitiva y
Conducta Humana, Instituto
Aparato Locomotor,
Universidad Austral de Chile,
Valdivia, Chile

4 Centro de Integración
Cognitivo Corporal, Santiago,
Chile

5 Center of Studies in Clinical
Psychology and
Psychotherapy, Universidad
Diego Portales (CEPPS-UDP),
Santiago, Chile

6 Instituto Milenio para la
Investigación en Depresión y
Personalidad (MIDAP),
Santiago, Chile

Introduction

Fibromyalgia is a chronic pain syndrome of unknown etiology characterized by generalized musculoskeletal pain [1], [2], [3]. Other symptoms associated with this disease are chronic fatigue, sleep disorders [4], [5], hyper-sensitivity to sensory stimuli [6], attention deficit, short-term memory loss [7], anxiety and depression [8], [9] and gross impairment of daily and work activities and the social relations of patients [10], [11], [12].

Fibromyalgia is a high prevalent disease [13], [14], [15], recognized as one of the most difficult chronic pain disorders to diagnose and treat [16], [17]. It is considered a functional disorder, characterized by symptoms, suffering, and disability, not by disease-specific abnormalities of structure or function. The heterogeneity of its symptoms and the absence of an evident organic correlate have led many to consider it “an invention” [18], adding to the difficulties faced by patients an extra dimension of social judgment. Often considered a somatoform and “central” (nervous system) pain disorder, fibromyalgia is a controversial condition that escapes from the current biomedical framework and challenges our established understanding of body function, health and disease [19], [20], [21].

While fibromyalgia is considered a syndrome with no cure [22], according to a study done by Walitt et al. [23], 10% of patients do have substantial improvement (see also [24]). So far very little attention has been directed towards the process of transiting from illness to recovery in fibromyalgia patients. Although the question about processes that can account for changes observed in a specific intervention have been considered pivotal for understanding the utility of a given intervention and for advancing in science [25], most clinical research focuses on the pathological state and the assessment of the efficacy of a specific intervention. While transitions have been studied in fibromyalgia patients [26], they have been studied with the focus on the ill state: the transition from being a healthy woman to being a woman living with fibromyalgia.

Given the long duration of fibromyalgia and the multiple interventions and therapeutic strategies that fibromyalgia patients might experience throughout the healing process, it seems relevant not only to study whether a specific intervention is effective or not, but to understand the process of recovery. Also, because no specific treatment has been proven effective for fibromyalgia, patients have a rather active role in their recovery process, looking for different strategies that range from home care and religious practices to the predominant biomedical devices (primary care, emergency, etc.). Studying recovered patients' experiences can inform us about trajectories, transitions, strategies, points of inflection, and insights that characterize the process from illness to recovery.

The notion of recovery is not univocal, particularly in the context of a chronic and theoretically incurable syndrome such as fibromyalgia. To problematize the understanding of the notion of recovery in the context of fibromyalgia, Mengshoel & Heggen [27] used the distinction between

illness and *disease*. According to the authors, disease refers to the organic dysfunction while illness refers to the subjective experience of not being well. Further, Mengshoel et al. [28] propose an understanding of recovery as the process involving the “making sense of what is happening and discovering how to recreate a dignified life within the limitations set by the disease” [p.3]. This is the understanding of recovery that is used in this study. Mengshoel and Heggen [27] showed that fibromyalgia patients recovered irrespective of any specific treatment. Their findings suggest that recovering involves reducing the divergence between patients' abilities and the social obligations they thought they had to fulfill. Grape et al. [29] explored the evolution of tiredness in women recovered from fibromyalgia. Their results suggest that developing an awareness of tiredness, allowing them to balance their expectations and capabilities, contributed to the recovery process. Wentz et al. [30] studied psychological functioning and psychosocial processes in recovered fibromyalgia women. The authors found that recovery was accomplished after a marked decrease in mental load resulting from improved life conditions or cease of overexertion of body and mind. According to the authors, recovery appears to rely on an improved self-regulation and less dissociative functioning.

Altogether, these studies suggest that recovery is related to resetting the boundaries of patients' daily tasks in terms of what they can or want to do. Until now, how this process of “boundaries resetting” occurs, from the patients' point of view, i.e., from a first-person perspective, has not yet been studied. How does this transition from what their body *has* to do towards what their body *needs* or *wants* takes place? How does this transition allow them to restore the body's homeostatic and affective balance? The aim of the present study is to explore the bodily experience of recovery of fibromyalgia patients, focusing on the changes that, from the patients' perspective, were significant in the process towards health. For this, we used qualitative, phenomenological and arts-based methods combining different levels of description: a narrative level using semi-structured interviews; an embodied level using the micro-phenomenological interview and body mapping, and a non-verbal level also provided by the body mapping method.

Methods

Participants

Women over 18 years of age diagnosed with fibromyalgia according to The American College of Rheumatology [1] were contacted through the database of the Pain Unit of the Hospital Clínico de la Universidad de Chile. A call to participate in the study was also published on the boards of the Universidad Diego Portales and the Universidad Central in Santiago, Chile. Thirteen women were recruited and participated in the first session of the study. Of these, five did not complete the study: four of them because of

Table 1: Socio-demographic characteristics of participants (n=8)

ID	Age	Gender	Marital status	Employed	Educational level
P1	66	Female	Separated	Retired	7 (Master's or equivalent)
P2	63	Female	Married	Retired	5 (Short-cycle tertiary education)
P3	38	Female	Married	Public administration	7 (Master's or equivalent)
P5	52	Female	Married	Sales manager	5 (Short-cycle tertiary education)
P7	67	Female	Married	Retired	7 (Master's or equivalent)
P11	37	Female	Married	Architect	7 (Master's or equivalent)
P12	48	Female	Married	Psychologist	7 (Master's or equivalent)
P13	48	Female	Single	Factory production supervisor	5 (Short-cycle tertiary education)

lack of time for the second session and one of them did not respond to our calls. The analysis was performed with eight participants. Of these, four were contacted through the Pain Unit of the clinical hospital of the University of Chile in Santiago and four through public announcements placed in the universities mentioned above. All the participants had a Latin American background, specifically they were Chilean women living in Santiago, with different educational levels (according to the 2011 version of the International Standard Classification of Education) and age range from 37 to 67 years old ($M_{age}=52.38$, $SD=11.92$; see Table 1).

The ethical protocol for the research was approved by the ethics committee of the faculty of Psychology of the University Diego Portales. Informed consent forms for the use of data for research purposes and related publications were signed by all the participants before the interviews. Participants were not paid but received a reimbursement to cover travel expenses incurred to participate in the study.

Procedure

An invitation was sent by email to the potential participants, briefly explaining the objectives and procedures of the research, and asking them for a telephone interview. The telephone interview included a screening questionnaire that also allowed a first assessment for eligibility. The screening questionnaire had different questions about demographics, medical information and others, to ensure that potential participants met the inclusion criteria for the study.

The main inclusion criteria were: having been diagnosed with fibromyalgia in the past; having been discharged from treatment in the case of patients coming from the pain unit, and no longer fulfilling the ACR criteria for fibromyalgia. Exclusion criteria followed the guidelines for a larger study that included measures involving the autonomic nervous system and behavioral body schema variables. Therefore, exclusion criteria included presence of eating disorders; use of drugs or excessive alcohol use; history of neurological conditions such as epilepsy, stroke, organic brain impairment, and dementia; autoimmune diseases or diseases affecting the autonomic nervous system; cardiovascular disease; diabetes mellitus; pregnancy; and amputees or a physical disability.

All prospective participants received an information sheet, consent form, and a questionnaire before partaking in the study. Data collection was carried out during two interview sessions with each participant. Each session lasted approximately two hours and sessions were carried out within an interval of approximately one week at the Faculty of Psychology of the Universidad Diego Portales in Santiago, Chile. During the first session a semi-structured interview was conducted and during the second session body mapping and the micro-phenomenological interview took place. The duration of whole the study was approximately four hours for each patient.

Materials and Instruments

The semi-structured interview

The semi-structured interview was self-constructed and oriented to our research objective (i.e., to explore the bodily experience of recovery in patients with fibromyalgia) following the guidelines described in Kvale [31]. The first researcher (C.V.M) built a framework of themes to be explored that included: the socio-emotional context in which the onset of the symptoms occurred, the process between the onset of the symptoms and diagnosis of fibromyalgia, the actions and reactions of the patient towards/regarding the diagnosis, the trajectory of medical consultations, the trajectory of complementary therapies (if any), what kind of measures the participant took in relation to her health, what kind of changes were made in her life, changes in personal relationships, changes in daily activities, changes in professional activities and "moments of new understanding" or key moments that marked the evolution of the disease and of the recovery process. Interviews were undertaken by C.V.M and D.D (see Attachment 1 for the full interviews).

The micro-phenomenological interview

The micro-phenomenological interview (MPI) is aimed at obtaining detailed descriptions of single life situations, focusing on the procedural dimension of the experience and from an embodied perspective [32]. It was first conceived of as an "Entretien d'Explicitation" by Pierre Vermersch to investigate the processes of learning and problem solving [33]. Its focus on the procedural dimen-

sion allows aspects of experience that are implicit, or that unfold in a pre-reflective dimension, to become explicit. A “content-empty or structure-driven” type of questioning characterizes the researcher interventions, rebounding on the words used by the interviewee. This type of intervention enables the researcher to obtain fine-grained descriptions reducing possible inductions. The type of questioning in the MPI does not focus on beliefs or opinions or judgments regarding a certain subject – in this case the recovery – but rather focuses on obtaining accurate descriptions of the actions involved in the development of a particular experience [34]. C.V.M and D.D, both trained in the method, conducted the micro-phenomenological interviews (see Attachment 2 for the full interviews). The specific aim of the interviews in the context of this study was to characterize one of the moments of new understanding identified during the semi-structured interview and chosen jointly by the interviewer and the participant. In order to facilitate contact with the experience from an embodied perspective, we performed a relaxation and body awareness exercise with the interviewees. At the end of the exercise, we asked the participant to get in touch with the chosen moment and the MPI began.

Body mapping

Body mapping is a visual, art-based process of creating a body-size drawing of the person's own body to express a certain aspect or process of people's experiences [35]. It was first used in 2002, in South Africa, as an art-therapy method for women living with HIV/AIDS [36], [37] and since then it has been used as a research method, therapeutic intervention and community development tool. Body mapping helps to draw participants' attention to embodied experience, revealing aspects of a person's experiences that are not easily expressed by words [38]. The guidelines of Gastaldo et al. [38] were employed and adapted to our research objectives and methodological framework. In particular, from the perspective of first-person methodologies, it is sought to guide the person to an embodied contact with experience by redirecting attention to how the experience is presented, i.e., these methodologies aim at helping the person to become aware and describe the internal actions and gestures involved in the presentation of a given experience. In body mapping as described by Gastaldo et al. [38], some of the instructions seemed to favor a position of reflection and rational elaboration on the experience in question rather than an embodied contact. For example, one of the instructions was: *Create a personal slogan (e.g., a statement, a saying, a poem, a song, a prayer, something you say for yourself) that describes your philosophy of life or your current thinking about your life.* Therefore, we adapted the body mapping for its application to this project, defining only a few previously established instructions and encouraging the creation of the body map from the bodily feeling and the descriptions of the moment of new understanding done during the micro-phenomenolo-

gical interview. Given that the moments of new understanding described a change in the participants' state, participants performed two drawings on each map: one representing participants' state before the change and another one representing participants' state after the change. Using the words used by the participant during the MPI, we first helped the participant adopt the position that she had before the change while the researcher traced the participant's silhouette in that position. The same process was repeated for the moment after the change. Then, also with the help of the MPI description, we encourage them to complete the map. Figure 1 shows the setting of the MPI and body mapping.

Interviews were audio recorded and filmed. Body maps were photographed and scanned.

Analysis Procedure

In order to answer the research question, the authors analyzed the data obtained through each of the three methods in accordance with each method's guidelines, as described below.

The semi-structured interviews were analyzed using Thematic Analysis [39], [40]. This sought to uncover patterns of meaning in the participants' account of their experience and to identify significant and important themes across their narration. Periodic meetings were held between the researchers in which the categories and their properties were agreed upon and the data triangulated. More specifically, following the guidelines of McLeod [41], the procedure of thematic analysis consisted in an initial coding of the interviews (by C.V.M), the examination of the codes looking for consistency and for common themes (by C.V.M and A.V.R), the revision and completion of the coding (by A.V.R) according to the criteria established in the previous step and finally the agreement of the final categories and their organization in superordinate and subordinate themes (by C.V.M, A.V.R, and J.D).

The micro-phenomenological interviews were analyzed by C.V.M and D.D following the indications described by Pettimengin, Remillieux and Valenzuela-Moguillansky [42] and Valenzuela-Moguillansky and Vásquez-Rosati [43]. This method works with the descriptions of the procedural dimension of situated experiences, hence removing descriptions that refer to beliefs, judgments, theoretical knowledge and general descriptions. The selected data was subjected to a diachronic analysis that aimed at identifying the temporal structure of the experience and a synchronic analysis aiming at characterizing the different phases or temporal units of the experience, as described in [43].

The body mapping was analyzed following the participatory analysis framework proposed by Guillian Rose [44]. In particular, to analyze the body maps, we used three sources of information: participants' verbatim accounts and field notes of the process involved in the creations of the body maps; participants' answers to the question “what do you see” at the end of the body mapping and



Figure 1: Realization of MPI and body mapping; from left to right: Micro-phenomenological interview; drawing the silhouette of the body map and painting of the body map

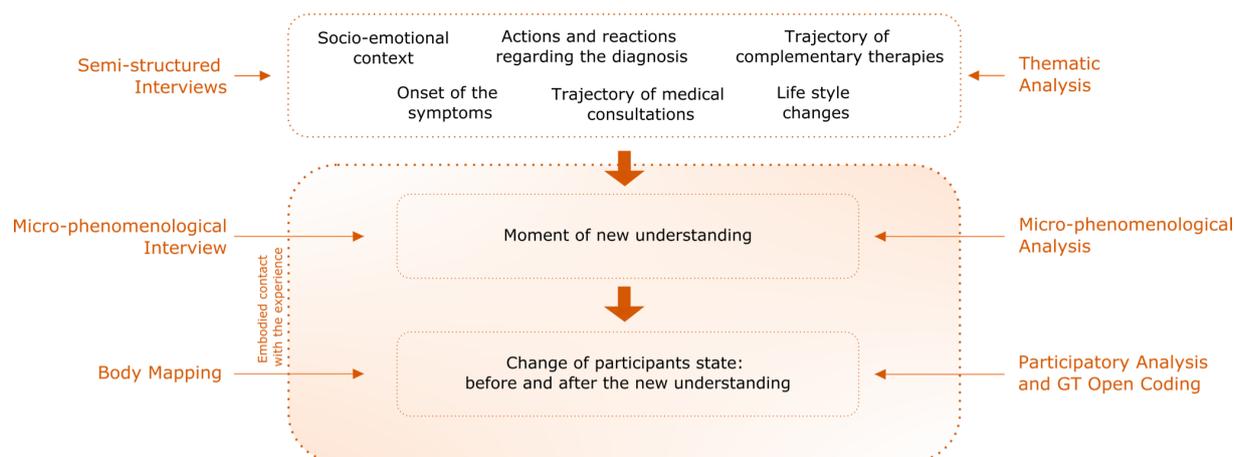


Figure 2: Summary of the collecting methods (on the left) and analysis methods (on the right); in the middle of the Figure are the topics that were explored with each of the collection and analysis methods.

the researcher C.V.M answers to the questions: “what do I see?”, “what do I feel?”, and “what do I imagine?” after looking at each body map. The last three questions were inspired by the role of the witness in the method authentic movement [45]. They aimed at relating to the body map and distinguishing the visual, somatic and interpretative dimensions of witness experience of the maps. Participant and researcher descriptions were qualitatively analyzed through Grounded theory open coding procedure, leading to main categories [46]. A summary of the collection and analysis methods can be seen in Figure 2.

Results

Thematic Analysis

Four overarching themes were identified from the qualitative data collected from the semi structured interviews. These themes seek to illustrate the participants' experience of fibromyalgia and their understanding of what it meant to have this diagnosis. The themes were:

1. Making it through the day,
2. Haunted by my body,
3. Making sense of my symptoms and diagnosis, and
4. Inhabiting my body.

Theme 1: Making it through the day

Although for most of our interviewees the diagnosis of fibromyalgia was not immediate, all participants in this study were able to identify – in retrospect – some aspects of themselves or of their lives that may have affected the development of the disease. Situations such as family crises or work-related stress, mental health issues and even early childhood events were mentioned as common factors in the life history of the participants, but at that time were not considered as having some connection to their pain. For them it was more about living in the moment, trying to move forward even while realizing that something was wrong, realizing they were in pain, but not paying much attention to it. Patients recognize “walking fast”, “being tired all the time” and “not taking care of myself” in order to “function” (P2: “I was always arriving tired [at home] and I was always neglecting myself. I neglected myself in everything, I never worried about my health.”). The pains appeared for many years (P12: “I think that the symptoms started before [the year] 2000, while I was young... I'm talking between my 15 and 25 [years old] more or less, I think that... some of them were associated to, to, to, to, I believe that some of those symptoms were related to... the family relationships, to my parent's divorce. I was fourteen when they got divorced”), but with little awareness or little idea that there may be something else going on (P11: “I mean, I do, I

have four kids, I am self-employed, I move around a lot and all that, but... then of course, one starts to get used to being tired, to get used to having a lot of work to do and suddenly you just get used to it, but suddenly you feel this, I felt everything and I said, I felt that this was a tremendous warning.”).

Theme 2: Haunted by my body

Each participant described how discomfort, pain and distress appear to have a life of their own, that they could not seem to control or understand. Their pain had different forms of manifestation such as discomfort in thighs and back pain, headaches, muscle rigidity, muscle pain, swelling in hands and knees, joint stiffness and contracted when waking up and extreme sensitivity (P12; And then I started having paresthesia in my legs, I had tingling, my hands hurt, my feet hurt [...] while I was doing my professional practice, I had one of the worst crises of my life, I could not walk. I walked with a cane, bent like this, 90 degrees”; P3: “Well, I got married and I was still feeling bad and I was still feeling physically in pain. It was very difficult for me to get up and in order to alleviate the pain they [the doctors] started to give me more drugs that disconnected me. Then I slept many hours a day and I was permanently in a state of being doped up, so it was like I was never very present...”).

Patients mentioned that these manifestations of pain did not seem to have much obvious explanation, that they could not connect them to anything in particular. Different symptoms were experienced and treated independently by different specialists, without a unifying explanation that would allow them to make sense of their symptoms. It was only when the pain becomes unbearable, as something they could longer ignore, that they begin to realize that their physical pain was also related to an emotional one. Participants talked about tiredness, sadness and depression that exacerbates their symptoms and compels them to take action (P2: “And I felt like I wanted to die so badly at that minute. Like it’s not the life I want to have. I’m not the wife I want to be. I’m not the mom I want to be. I’m not the professional I want to be. I don’t want this life; I don’t want this life”; P13: “And a lot of stress at work. And then one day I woke up, I looked at myself in the mirror and I felt that I was not me. I mean, I didn’t recognize myself at all. And then I started with everything, with more pain, with more things.”).

Interestingly, most of the participants described that it was precisely at times in their lives of greater stability and calm, when some stressful situation had already passed (such as after periods of financial instability and precariousness, or the illness of a loved one) that the pain manifested itself most strongly (P11: “[There was] a part, a part of me that got calmer and it was like as that part was calm, then another part of me says, ‘Yeah, since I’s all calm here, now I can manifest.’ And that was the body”; P3: “In the summer of 2014 we went on vacation with my partner at the time, who is my current husband, and my son. And I started to notice that I was extremely

tired. I remember we went to C... and I was falling asleep during all the stretches of the trip [...] I didn’t have the energy to do anything. I was very sensitive to the cold, my shoulders and head hurt a lot [...]. And it was like [after everything I had been through] my life was just taking shape, so it was like, – No, really! This can’t be happening to me *now*”).

Theme 3: Making sense of my symptoms and the diagnosis

Most interviewees reported that their pain initially intensified upon diagnosis and that they felt they finally had permission to feel it. They contacted their pain and stopped avoiding it (P12: “I mean, I went on with my life, uh... I started to be more careful and more attentive to the pain I had. Because until before it was like, like I didn’t... like I didn’t feel them, I felt them, but I didn’t take them into consideration”; P3: “But that stage was very hard physically and emotionally, because somehow the symptoms intensified when I was diagnosed.”). Some patients had heard about fibromyalgia before, others had not, but either way, the diagnosis in itself did not seem to be enough to make sense of it. For others, diagnosis produced a certain amount of relief in knowing that their pain was not made up, that they were not exaggerating, and that what they felt had a name. However, they also had the sensation that they did not know what to do with it. Knowing that this illness is chronic scared them and they felt alone and misunderstood by others (P3: I didn’t understand, I mean I had never heard the word [fibromyalgia]. I started looking for what fibromyalgia is. I found horror stories that it was chronic, that it was painful and terrifying, like terror.”).

Participants described a long therapeutic itinerary that goes from traditional to complementary medicine, psychological counselling and contemplative or somatic practices. During this process, patients looked for solutions to reduce or end with their pain (surgical, non-surgical and/or pharmacological interventions). This therapeutic itinerary did not end with the diagnosis of fibromyalgia, but rather the diagnosis invites patients to find something that makes sense to them: to understand the relationship of their life history with pain (P12: “it moves me and I am grateful to pain because it has made me more, more human [...] it is difficult to always be in pain, but I also have to be very grateful for the pain, for everything it has allowed me [...] this physical pain has helped me to become aware of the pains, the emotional pains.”).

Theme 4: Inhabiting my body

Slowly the interviewees were able to develop a better understanding of their disease, that their pain is not aleatory but associated with stress, high levels of self-demand or different emotional situations that take place and that this needed to be addressed in order to relieve the pain (P12: “Yes, I am a better-treated neurotic, more conscious. So, I now am more aware when I begin, when

I get into my neurosis, and I bring myself back. But it was, it was related to an extreme, eh... eh... self-demand.”; P1: “Maybe the disease itself, that is, in the sense that knowing that as long as I am tense or whatever, that doesn't do me any good. Just as it is not good for me to get angry for no reason, and that was my natural tendency to get angry about everything.”).

Patients also understood that their pain was a wake-up call, it was their body speaking and it was necessary to pay more attention to it. The interviewees talked about becoming aware, and that this became a permanent effort to listen, to be conscious of one's own sensitivity, to learn to say things, to lower their self-demands, and “change the natural tendency to keep moving”. They also learnt that being tense, getting angry or getting stressed does not do them any good and that they must regain the familiarity of inhabiting their body (P13: “For example, I know that if I am having a pain crisis... it is because my body is already... asking for help to calm down, that I have to stop, that I have to rest and, and, and, and what is it called? Like loving myself a little bit more and giving myself a treat.”; P11: “I was able to become more aware of my sensitivity. Of course, because all of a sudden you want to feel super... superwoman regarding work, family, everything. And I let that go.”)

The possibility of inhabiting their body allowed the participants to relate differently to their symptoms, to their own bodies, to themselves and others. This new form of relating was experienced as living more freely and learning to take care of themselves, which seemed to help the crises diminish in intensity and over time. Interviewees mentioned that they had to learn how to relax, learn to say no and to put boundaries on their relationships. They also understood they had to learn to let go, to care and take care of themselves and stop putting themselves last (P5: “So now no, I have had to learn and force myself to say, ‘no, I don't want to, I can't, say no’ [...] And also, you know, how to stay away from problems. From people that you say, well, people that sometimes have a lot of problems and they kind of make you part of their problems, like when they say toxic people. [...] So you know what? It has been like putting fences. Like me, I always say protect yourself...”; P3: “I don't have the same life I had before. And I am not the same person I was before. And I have had to go a long way to try to love the person I am today. A person who gets tired faster, who has to be very attentive to all the signals of her body.”).

Micro-phenomenological interview

The analysis of the MPI allowed us to identify a diachronic structure of the moment of new understanding composed of three major phases:

- Phase 1: State of tension and rigidity,
- Phase 2: New understanding, and
- Phase 3: State of openness and connection as shown in Figure 3.

Phase 1: State of tension and rigidity

The first phase refers to the participants' description of the moment prior to the new understanding, characterized, as its name indicates, by feelings of tension and rigidity. In three of the participants this state describes a crisis of pain or tension where, in addition to tension and stiffness, the feelings of extreme tiredness, intense pain and heaviness were experienced. In addition to these bodily sensations, there was also a feeling of fragmentation, of not understanding what was happening, a feeling of loneliness and also ruminative thinking (P3: “[I felt] as if I weighed 200 kilos. A heavy body, I can't move a finger in bed. Staring at the ceiling. Watching the time go by. Lost in my thoughts, wondering why, what was happening to me, what I was going to tell him, what I was going to do with my son [...] I was kind of fragmented in a way, because when you're not diagnosed yet, you have a lot of ideas in your head, people tell you a lot of things”). In such cases, the state of tension and stiffness is associated with a disconnection with the outside, the participants describe being completely submerged in their inner state of pain, tension and stiffness that in some cases is expressed in the form of anguish (P7: “And it was all clenched, fists, arms, legs, back. I was in pain. It's – the anguish is – especially here. It's like a – a thing here [...] that radiates [...] No, I don't perceive anything from the outside, it disappears”).

For four participants, the state of tension and rigidity was not linked to a context of pain crisis, but to situations in which this state was presented as a reaction to some situation in their daily lives. In such cases participants described muscular tension and feelings of rigidity and hardness that sometimes affected their breathing patterns (p12: “...In the body, because it's like everything gets tense. It is like that, it is a micro tension, like that, [shortness of breath], it is like my breathing is cut off a little bit like that [shortness of breath]”). They also described a state of alertness; a feeling of uneasiness, in some cases of fear, a feeling of having to protect themselves from something that was not clear or explicit to them (P11: “it's like that's why I get stiff, because: it gives me like a, like a... fear... what she's saying to me”).

There was only one participant whose narrative did not allow us to identify the description of this first phase explicitly. In her case, the description corresponding to the situation prior to the moment of new understanding referred to the general context of years of experiencing pain of various types, which were always treated in isolation.

Phase 2: New understanding

In the second phase, which can be considered the new understanding itself, we could identify a micro-dynamic consisting of three processes. In three participants this micro-dynamic consisted in the sub-phases: *Allowing oneself to feel*, *Pondering what is felt*, and *Changing behavioral patterns* as shown in Figure 3. On the other three participants instead of the sub-phase *Pondering what is*

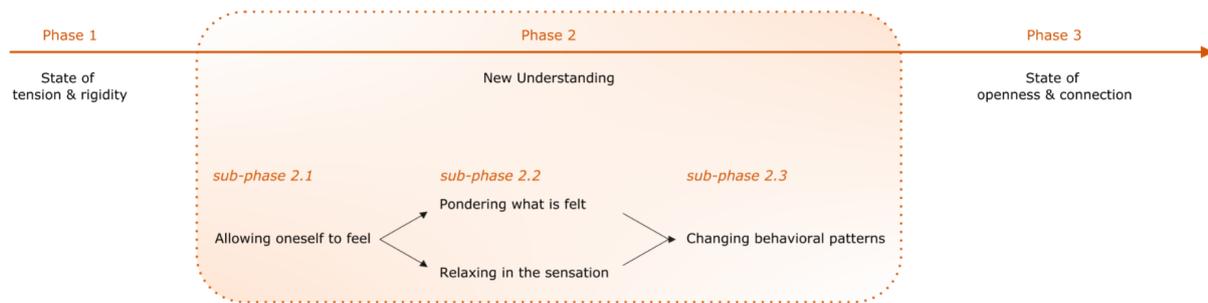


Figure 3: Diachronic structure of the moment of new understanding

felt, participants described the process of *Relaxing in the sensation*, which in turn led to the change in the behavioral patterns as illustrated by Figure 3. The two remaining participants only described the change in behavioral patterns.

2.1. Allowing oneself to feel

This sub-phase groups the utterances referring to attending to bodily sensations. In some cases, these sensations were pleasant (P12: "...becoming aware of how I am. It's like...perceiving, perceiving. Yes, perceiving the water, the sun. Eh.... and feeling how my body relaxed. I put the attention on the muscles. Eh, I put, my, my, my attention on... on that, on, on, on the skin [...] my skin is like... it is feeling the sun, the air... and, of course, it is like, like there is a limit there [...]... it is like a limit... it is flexible... that, me, it is... and me... it differentiates me from the not me [soft laughter], I don't know how to explain it. It's like, here in the skin there is the sun and there is the air which is what is outside of me and what is inside of me. It's like a boundary that allows me to be more aware of what is inside me"). In other cases, the sensations were unpleasant (P5: "I felt in my back... the... the pain of all the sensations I experienced so many times, that anguish, that waiting, when he got us up at two o'clock in the morning so that we could go sit with him [...] I felt it"). Also, there were cases that the sensations had no specific valence (P11: "I feel the warmth, I feel... I feel that movement she makes with her hands... I allow her... to do that... and I am in myself and in that movement").

2.2.a. Pondering what is felt

Regardless of whether the sensations were pleasant, neutral or unpleasant, three participants described processes that were grouped under the category of *Pondering what is felt*, which ranged from valuing and evaluating what was felt, to associating what was felt with previous experiences. For instance, P 12, described a process that allowed her to value the pleasurable sensations she was feeling ("I calm down and... I take a breath and then I realize what my desire is. I want to be here more than I want to be there. This is what I want. Of course, I want to be here. I even laugh, you know, again I laugh, I laugh... I think about going there, but I want to be here. And I say

to myself, "No, I'd better stay here. I feel like staying here. It's more pleasant to be here").

In the case of P1, the process involved an evaluation or reconsideration of her behavior based on what she was feeling ("I was walking fast and saying, "But why? I'm not in a hurry". I am aware that sometimes, walking fast, it starts to hurt a little bit here, what do you call the front part, the shin? [...] I laugh, I laugh at myself. I find it so absurd, I find it so absurd to go fast if I'm not in a hurry, if nobody is waiting for me, you know what I mean?").

P5 engaged in a process of association of what was felt with experiences from her past ("Ehm... as if all that... the feeling of not understanding, the anger, the crying, the feeling that I had so many times as a child of being sleepy and..., like.... all those negative feelings, I saw that they turned into pain in my back").

Despite being different types of processes, they all allowed participants to establish contact and gain familiarity with the sensation, rather than rejecting or ignoring it.

2.2.b. Relaxing in the sensation

This category groups the statements, described by three participants, that referred to the process of letting go, relaxing, and being present to the different body sensations as well as letting go of thoughts or questions that were contributing to the tension and rigidity described in the previous phase. Similarly, to *Pondering what is felt*, relaxing in the sensation also allows gaining familiarity with the sensation but in a less analytical manner (P11: "as she is doing her work, I'm like, I'm loosening up to... to what she is doing. She starts to massage my arms and, and ... I start to let go. The questions start to fade away [...]. What was rigid is released. It, it, it loosens up, the questions.... It's as if the intellectual stuff is loosened [...] it's as if I loosen up... It's not 'me' that let's go, it's like it lets go.... And, and I can enter into myself").

2.3. Changing behavioral patterns

This category groups the statements that describe a process of change in behavioral patterns. In the different participants, these patterns could be of different types. For instance, the way they perform certain daily actions (P1: "At the beginning it feels forced [...] it's like walking fast and suddenly slowing down. I mean, it's weird, it's weird. So, I take it as an exercise"); the way participants

relate to themselves (P12: “is like, it’s, it’s, it’s me talking to myself, it’s an internal dialogue. It’s my voice. It’s relaxed, it’s fun. And the kind voice comes up and I laugh and [...] it laughs, it’s funny. And... and relaxed”); and consequently, the way they relate to those close to them (P2: “And I said to myself – it is me; it is my health, it is my cure. Especially my cure, because... the psychologist, the psychiatrist, they always told me that... I had to love myself, to do the things I wanted, but as I said, out of fear, out of fear, out of fear, I don’t know, eh: I didn’t do it, but not now, now I....I... put off many things, for instance: not going to the kinesiologist, not going to the swimming pool, not going to anything. I... I went home, waiting for my husband to arrive, to prepare lunch, to take care of him, everything. [...] And then I said, “I am going to turn my life around, I am going to do everything I have to do for me”). Also, the change could be about the way they relate to their body and their symptoms (P3: “I hadn’t realized until that minute that whenever I talked about my body, I spoke in the third person. [...] As if it were another person different from me. And it wasn’t so clear to me, until that moment that it seemed like I was effectively separating what I am, from the body that I have [...] it was the first time that I started to say, instead of – I have this disease, – I have this diagnosis”).

Despite their differences, all types of changes led participants towards a greater connection with themselves and familiarity with their limits, with what they wanted to do, with what they liked to do, and towards a greater consideration of, and respect for, their own person.

Phase 3: State of openness and connection

This phase is characterized by a different relationship of the participants with themselves, with their symptoms and with the outside world. Sensations of relief, relaxation and freedom are experienced (P3: “And I was – I was super relaxed. Like I felt my body was lighter [...]. At that time I wasn’t worried about anything [...] in that hour or in that hour and a half, I had really felt less stiff, lighter, less weight on my shoulders”).

The body appears light, flexible, relaxed and at the same time providing support, stability and security (P1: “If I walk slowly, something else is happening, it’s like there is more movement, more... [the arm] is loose, it is loose, everything is loose, it is looser, [there is] more flexibility [...] the density is going to be on the back. Density in the sense, I don’t know, whatever, but it is density [...] I feel the body more, but not in the sense of heaviness, [the density] is in the supports [...] The arms are light, they are light... [...] the legs... the legs... I want, I want to illustrate... lightness, [...] I don’t know how to illustrate lightness... harmony, eh, lightness and at the same time density, because it is, it is, it is feeling, but at the same time it is calm, it is without greater, without greater weight, but, but, but, but, but, but it is more, it is denser, it is more harmonious”).

The body is no longer synonymous with tension and pain but a “kind” body appears capable of providing enjoyment

and satisfaction (P7: And light, my body gets lighter [...] it gets lighter, it is a kind body, because when it is like that [in a tense state] it is a body that is against you, like an enemy. [laughs] And so [in the light state] it is a kind body. Kind because it relaxes and it’s allowing me to flow, even more positive thoughts.)

Participants also manifest a greater connection and openness towards the outer space, which is no longer shown as threatening but as familiar (P7: “Yes, I started to connect with the outside [...]. I look out of the window and I look at the plants and the – the – the – the landscape that is seen from my window, from the bedroom and I’m glad. I listen to the birds and I’m glad. That’s it. There, I begin to connect with the outside world [...]. All that happens in the whole process of relaxation. In the process of relaxation, I become more and more sensitive”).

This phase is also characterized by descriptions of empowerment; of seeing and accepting themselves, of feeling the ability to have a say in the direction of their lives and of seeing future perspectives opening up (P5: No, you know it’s like the feeling of..., of, I don’t know how I could say it as a feeling, but it’s like the feeling of certainty, that now I will have the reins of my life, like there will no longer be a ghost that, that will always be reminding me of that moment. Ehm... And that feeling gave me certainty [...] it was like finding myself and feeling strong, like I had the capacity to improve myself [...] in that minute I walked and I realized that I could heal myself, that it was in me to heal myself, and... to feel light in all those blocks I walked. ... and at some point, as I was telling you, I felt like... as if a breath, a halo, a light, a soft wind had arrived... and doing this, what I am doing now deep down, is to breathe and say, ‘I am healed’ [...] it was like a feeling of fullness. Like: ... and in that feeling of fullness there were several [sensations]. What I was telling you, to feel light, eh..., to feel myself, to feel strong, but that strength was linked to having the capacity to take my life, to heal myself.)

Body maps

The analysis of the body maps (Figure 4) allowed us to identify three main categories: visual features; felt features and dialogic relationship and their properties (see Table 2). The former two categories allowed the identification of distinctive features that characterized each of the moments that were portrayed in each body map; the *State of tension and rigidity* and the *State of openness and connection*. The third category allowed the identification of relational features between the two portrayed moments.



Figure 4: Body maps; from top to bottom and left to right P1, P2, P3, P5, P7, P11, P12, and P13; each body map contains the representation of both states: the one before and the one after the new understanding.

Table 2: Summary of categories and properties characterizing the body maps

Categories	Properties	Description of the category	Configuration of the properties before and after the moment of new understanding
Visual Features	<ol style="list-style-type: none"> 1. Color 2. Shape 3. Size 4. Disposition 5. Texture 	It refers to the descriptions of the body map features distinguished through the visual modality.	<p><i>State of openness and connection</i></p> <p>The drawings were characterized by lighter shades of green, yellow and orange; larger body sizes; and "solid" painted body parts.</p>
Felt Features	<ol style="list-style-type: none"> 1. Openness 2. Warmness 3. Tonicity 4. Fluidness 5. Attitude 6. Nutritive character 8. Expansiveness 9. Brightness 10. Quietness 11. Lightness 12. Harmony 	It refers to the descriptions of sensations and feelings generated by seeing the body map.	<p>The drawings evoke the felt dimension which was characterized by the sensation and feelings of openness, warmth, softness, fluidness, welcoming attitude, fertile or nutritive character, expansiveness, brightness, firmness, quietness, lightness, relaxing, freedom and harmony.</p>
Dialogic Features	<ol style="list-style-type: none"> 1. Salience 2. Relationship 3. Common elements 	It refers to relational aspects of the images portraying each of the moments.	<p>Most of the time, the body map drawing that represents the <i>state of tension and rigidity</i> is hidden by the figure that represents the <i>state of openness and connection</i>. Also, there is a relationship between both drawings (e.g., embraced, conflicted or surrendered). In some cases, common elements to both figures established a unifying link between them.</p>

Visual Features

This category refers to the features distinguished through the visual modality, trying to separate them from affective associations or interpretations. Five properties were identified: color, shape, size, disposition, and texture. The configuration of the values that these different properties took in the two drawings, before and after the moment of new understanding, were characteristic. Thus, the drawings that corresponded to the *State of tension and rigidity* were characterized by darker colors in shades of blue, black, brown and red, in contrast to the lighter shades of green, yellow and orange that characterized the *State of openness and connection*. In terms of shape, sharp edges and more vertical forms were distinguished in some of the images portraying the *State of tension and rigidity*. The posture of the body in general was shrunken in the drawing of the *State of tension and rigidity* and its size was generally smaller. In relation to texture, in some body maps it is possible to distinguish incompletely painted or "marbled" body parts in the *State of tension and rigidity* in contrast to "solid" painted body parts found in the *State of openness and connection*.

Felt Features

This category refers to the feelings and sensations generated in the interviewees and researcher by the body map. Twelve properties were identified: openness, warmth, tonicity, fluidity, attitude, nurturing character, expansiveness, brightness, quietness, lightness, and harmony (P5: "It's like a feeling of being able to stretch as far as one can stretch. It's a sensation as if I would need more space than the one there is in the paper to stretch myself, it's like feeling big, like infinite. I don't feel restricted in my body"; P11: "Well, uh..., well, uh I see a very radiant image. That is the first word that came to me. Very radiant, very fertile, that's why... the leaves, the nature. In a natural space. And... and this image came to me, like muscular [laughs] in the arms. Like strength, like this. Like firmness, like this. And well, this orange is this sensibility").

It seems relevant to clarify that these properties refer to the spectrum of possible values that each property can take. Thus, for instance the property of "openness" includes the possible values "semi-open" and "closed". In this way, when looking at the image representing the *State of tension and rigidity*, seven of the twelve mentioned properties were present. Thus, sensations such as coldness, rigidity, aggressiveness, restlessness, lack of firmness, contraction and tension were described (P1: "Uh, what can I tell you there. Of course, that's the attitude. It's rigid... therefore, for me, it's cold...". P12: "And this (the blue silhouette) tends to elongate, to contract. Like vertical [laughs] Vertical, it's like... it's tense, because it could be tense sideways, but this is tense vertical, it contracts.").

Dialogic Features

This category groups the descriptions referring to relational aspects of the images depicting each of both moments. Three properties were included in this category: salience, relationship and common elements.

Salience refers to the notoriety of the figures portraying each of the states for the observer. Many participants refer to the fact that when looking at the body map, only the figure representing the *State of openness and connection* appeared. The other was somehow hidden. (P2: "Well, I see... more than anything else..., the outside shape catches my attention"; P3: "I'm having a hard time seeing the first drawing [the one illustrating the State of tension and rigidity]. Like – like it's like these questions of form and background, what do you see first? I see the second drawing"). Also, the *State of openness and connection* was the one that was most thoroughly described by most participants when answering the question "what do you see?".

Relationship refers to the associations, generally speculative, established by the observer of these two figures. These associations were only identified in descriptions made by the researcher when answering the question "what do you imagine?" (R-P2: "I imagine that the green body embraces the black body"; R-P3: "I imagine a conflict between both bodies, one that emanates power, freedom, energy and the other that sucks and complicates it"; R-P7: "I imagine that the yellow silhouette is floating, gently surrendered and at the same time embracing the shrinking silhouette, unaffected by her intensity and pain, but welcoming it").

Common elements groups the descriptions of elements common to both figures that establish a unifying link between them and somehow a common source (P3: "And even though they're in different positions and obviously in different moods, they're still crossed by the same heart and pieces of energy that are the same"; R-P5: "I imagine that the green leaves grow from the yellow woman's body and that the green hand at her throat is of the same nature as the leaves"; P11: "A necklace. Yes. And earrings. Yes... Mhm, where in the first drawing I saw these... tears... in the second drawing I see this [a necklace and earrings]").

Discussion

The present study explored the subjective bodily experience of recovery of fibromyalgia patients with qualitative, phenomenological and arts-based methods. The different descriptive levels used in this study allowed us to deepen our understanding of the recovery process of women with fibromyalgia by looking at it from different aspects of the first-person perspective.

The analysis of the semi-structured interviews, which gave us a broad view covering from the onset of symptoms to the time of the study, allowed us to identify four main themes: *Making it through the day*, *Haunted by my body*,

Making sense of my symptoms and diagnosis, and *Inhabiting my body*. These themes gave us a general outline of the participants' process of change, not only regarding their symptoms and disease but of how their relationship with themselves also changed.

In line with the theme *Haunted by my body*, previous qualitative studies have described the relationship that fibromyalgia patients have with their bodies as of estrangement, where their body hinders the realization of their life, that it imprisons them, and frustrates them (e.g., [12], [47], [48]). Our study contributes to this idea and as Mengshoel et al. [28] have suggested, the fibromyalgia symptoms seem to generate a separation between the person and her body experiencing it as "a stranger and an object for scrutiny that disturbs social life in various ways" [p.3].

In our study, collecting descriptions of periods prior to the onset of the most disabling symptoms allowed us to put this experience of estrangement in the context of a process, which to our knowledge has not been described in other studies. In this way, we identified a previous stage, characterized in the theme *Making it through the day*, which suggests that there are already signs, prior to the onset of fibromyalgia itself, of a lack of connection of patients with their own bodies. Participants shared certain behavioral patterns, such as being highly self-demanding and neglecting themselves systematically, not being able to give attention to, for instance the tiredness they were feeling, showing signs of already distancing themselves from their bodies and sensations, what can favor the process of organic dysregulation characteristic of fibromyalgia. We think these findings are particularly important, because they show that the onset of fibromyalgia is not sudden and "out of the blue" but has a particular story that evolves over time. It also makes us wonder if early identification of these symptoms and a better relation with the body could, in some way, prevent or diminish the intensity of the crisis and musculoskeletal pain.

Interestingly, the quest that participants embarked on to alleviate their suffering once their symptoms were no longer ignorable, led them to search for making sense of what they were experiencing, getting in touch with their limits as well as their needs and desires. This process was addressed in more detail through the analysis of the micro-phenomenological interviews of a concrete moment of new understanding. Here, we identified that going from a *State of tension and rigidity* towards a *State of openness and connection* was mediated by a micro-dynamic initiated by the movement of allowing oneself to feel. From our study we cannot determine what it is that leads the participants to allow themselves to feel. However, we can assume that the conditions conducive to this possibility are established throughout the whole process that the participants embark on, to make sense of their suffering. This process is represented in the theme *Making sense of my symptoms and diagnosis* and the multiple encounters they have throughout their therapeutic itinerary. In this regard, coherent with our initial understanding of the notion of recovery and in line with the distinction

made by Mengshoel and Heggen [27] regarding illness and disease, our results showed that for the participants, recovery was more about making sense of what they were experiencing than completely ceasing to experience symptoms. While managing their symptoms and managing to take charge of their lives again, participants still experienced relapses from time to time.

Furthermore, our results show that for most participants, beyond the disappearance of pain and other disabling symptoms, the recovery process involved a reestablishment of the relationship with themselves in which they gained closeness with their feelings, sensations and desires. Our results show that being able to get in touch with bodily sensations, whether pleasant, unpleasant or neutral, by becoming aware of them and pondering or relaxing into them, allows changes that appear to be crucial in the recovery process. Returning to the evidence presented in the introduction [27], [29], [30], which shows that recovery is related to improved self-regulation and decrease in dissociative functioning, it can be hypothesized that getting in touch with one's body sensations contributes to the process of "boundaries resetting", key for self-regulation.

It may seem paradoxical that allowing oneself to feel appears to be a key aspect of the recovery process of a chronic condition such as fibromyalgia that is characterized by feeling pain. However, considering these results from a regulatory mechanisms perspective, it is not. Currently, the most accepted model that explains the symptoms of this disease is based on the regulatory mechanisms of the stress response [49], [50]. This model proposes that chronic pain can be a consequence of deregulation of the autonomic nervous system triggered by the presence of a stressor and favored by genetic predisposition (e.g. [51], [52]). While genetic predisposition might facilitate the onset of this syndrome, emotional regulation, processing and awareness seem to be crucial for both the onset and the development of the disease [53], [54]. van Middendorp et al. [55] examined differences between women with fibromyalgia and control women in different emotions and emotion-regulation strategies. Increased negative emotions and decreased positive emotions, as well as increased emotional-avoidance strategies, were found in women with fibromyalgia. Further, emotionally avoidant strategies were associated with higher levels of negative affect. Among the avoidance strategies, difficulty in identifying feelings was the one that was most strongly associated with negative affect, and also associated with pain and fatigue. Conversely, van Middendorp et al. [56] and Geenen, et al. [57] showed that expressing emotions was related to less pain and fibromyalgia symptoms.

Our results are in line with the previously described models of fibromyalgia and coherent with the embodied affectivity model [58], [59]. According to this model, interoceptive and exteroceptive feedback from the body allow the subject to attune or, to bodily resonate, with the affective qualities of the environment, meaning that body awareness involves emotions awareness and expres-

sion. In order to be able to identify our feelings, we have to be in contact with our bodily sensations and to recognize them. The bodily attunement or resonance provides the subject with tools for self-regulation strategies. Under this view, motion, body posture and emotion are intrinsically connected. Accordingly, a painful body that adopts particular motor patterns and posture, will influence interoceptive and affective awareness and vice versa [60]. According to our results, the fact of being able to sense, either pleasant or unpleasant sensations, through weighing the sensation or relaxing into it, enables a change – the "boundaries resetting" mentioned above – that in turns involves a change in the participants' relationship with themselves, moving from a state of tension and rigidity to one of openness and connection.

As presented in the MPI results, this state of openness and connection was described by one participant in terms of experiencing her body as being a kind body. We find it relevant to highlight the fact that the word "kind" is the translation of the Spanish word "amable", which was used by the participant and literally means "that which can be loved". We find the use of this specific word interesting in the context of the process described by the participants, as it signals a radical change in the participants' relationship with their bodies. This change is illustrated in the body maps.

The body maps allowed us to include a pre-reflective, sensorial and non-verbal level of description that complemented the analysis of the micro-phenomenological interview. The maps portrayed two bodies that contrast in various aspects such as shape, color, posture as well as the associated feelings these images produced. This way, the *State of tension and rigidity* was characterized by darker colors, smaller and shrunken silhouettes depicting sensations of rigidity, coldness, aggressiveness, restlessness, lack of firmness, contraction and tension suggesting an overall movement inward that isolated them from the exchange with the environment and others. On the contrary, the *State of openness and connection* was characterized by lighter colors, larger and expanded silhouettes depicting sensations of openness, warmth, softness, fluidness, welcoming attitude, fertile or nurturing character among others, suggesting an overall movement outward that possibilities exchange with the environment and others. Considering the described differences in terms of inwards and outwards movements might help us to understand the relationship between the present results with our findings of a previous study.

In a previous study, we assessed exteroceptive body awareness of people with fibromyalgia by using a body-scaled action-anticipation task. This task measures, in a covered way, the size (particularly the width) that the participants estimate their body to be [10]. Our results showed that fibromyalgia patients overestimated their body size in comparison to a control group, which, at first glance, appears to be contradictory the results obtained from the body maps (i.e., the state of tension and rigidity – where participants are in pain – depicted smaller than the state of openness and connection). Further, we found

a negative association between body-size overestimation and the *Body Listening* dimension of the Multidimensional Assessment of Interoceptive Awareness (MAIA), indicating a higher body-size overestimation among subjects with lower tendency to actively listen to the body for insight. These results suggest an interaction between the perception of our body in relation to space and posture and the awareness of our inner state. It can be hypothesized that patients in a state of pain, as was the case in our previous study, are undergoing this process of inward movement in which they disengage from their body, relating to it as a kind of prison or shell. This sore shell, of reduced functionality, repels what is around it to protect itself from stimuli that appear as threatening, contributing to the vicious circle that leads to isolation. This disconnection from one's own body, both in terms of body awareness and functionality, can lead to the perception of "carrying" a larger body than one actually has. On the contrary, in the case of the state of openness and connection described by the participants of the present study, the outward movement allows the patients to expand, inhabiting their space, becoming permeable to their environment and allowing exchange. This could allow for a more accurate estimation of the size of one's own body.

In addition to the contrasting aspects of the two silhouettes present in the body maps, the analysis allowed us to identify common elements: the heart that crosses the two bodies, the tears that are at the same time the beads of a necklace. This indicates that in this process of change, the patients also recognize a unity or continuity, something that was already present in them and that somehow is reframed allowing such change.

Methodological considerations

As stated above, the aim of our study was to explore the subjective bodily experience of recovery of fibromyalgia patients. Our results showed a change in participants' body awareness throughout the process of recovery. At the same time, the three qualitative methods used in this study can promote body awareness by generally encouraging participants to get in touch with their experience, and with their sensed bodily experience in particular. Through use of the semi-structured interviews, self-awareness was obtained by asking participants to reflect upon, and narrate, their experience and the recovery process. The MPI sought to bring the interviewees into contact with, and evoke, a particular significant experience, generating an awareness of the body that transits between feeling and reflecting on. Finally, in body mapping, the interviewees were asked to connect in an embodied way with their own body and the experience of recovery was anchored in the drawings. The question can be raised as to whether it is a problem to explore body awareness through methods that actually promote it? Can this be considered a limitation of this study? Can it be considered a strength? The question can be broadened to become relevant to arts-based research [61] and to the study of experience in general: is it a problem to ex-

plore subjective experience through methods that promote contact and awareness of it?

This question is part of a more general discussion of the challenges facing the study of experience in the context of scientific research [62]. In this regard, and relevant for the context of the present study, we have argued that the study of experience must consider its dynamic (i.e., experience is an always changing process), transformative (i.e., the very act of inquiring into experience transforms the experience in question) and self-referential character (i.e., experience is both the object of study and the means by which we study it).

Taking these three characteristics seriously, and wanting to be consistent with them in our research practices, leads us to question some of the requirements of objectivist science. In particular, the requirement that the researcher does not *intervene in* the study, nor do the tools used *modify the* "object" under study. Although our study did not have a therapeutic intent, during its realization we noticed that the activities carried out during the two sessions had an impact in this direction on the participants. The interviews, the relaxation exercise, the body mapping, and perhaps simply listening to them, had an impact on the participants that surely transformed in some way the experience they were describing, making them aware of aspects of their experience that they had not perceived until then. This was generally perceived as something positive by the participants, and in some cases received with great joy and surprise (for example, P3: "Mhm, it's nice to realize that, because in general in my madness, I think I'm more visible, when I'm doing more things, in tension, you know? Like I'm more visible to others or more present to others if I'm in the state of doing.... But now I look at it and no! I take up more space in (the relaxed state), I don't know, it's a spatial thing [laughs], but it makes me realize that.").

As described in detail in Valenzuela-Moguillansky and Demšar [62], the aforementioned questioning of the objectivist framework leads us to propose the study of experience within the enactive framework [63]. Here, the fact that with our methods we can transform what we are studying is no longer considered a problem but a given condition. This leads us to the recognition that when we inquire into the experience of another, we do something to that other and to her experience; her experience changes, it is transformed, and this may have important consequences for the life of that person. In this sense, recognizing the transformative character of researching experience should involve adopting an ethical stance towards our inquiries. In practical terms this could mean, designing our studies not just based upon data collection criteria but also considering the potential consequences that designs may have for participants (beyond the standard ethical considerations).

The discussion of the challenges facing the study of experience mentioned above also points to the need of including alternatives to verbal expression to communicate an experience [62], [64]. Researchers using first-person methods have observed that there are situations in which

words are not enough to express a given experience or aspect of it (for instance “unspeakable” and “ineffable” experiences; cf. [65]; see [12] for an example in the context of the experience of pain of fibromyalgia patients) and that the inclusion of alternative languages seems necessary.

In the present study, the inclusion of body mapping allowed the addition of a non-verbal descriptive layer that enriched the understanding of the participants' experience. In addition, this method also allowed us to enrich the verbal descriptions of the micro-phenomenological interview. In many cases, participants who did not manage to deepen their description during the MPI did so during the body mapping. For example, P1, at first had difficulty getting in contact with her experience and gave a rather scarce description. Then, when she had to create the body map, which was also difficult for her, she had to place herself again in the moment of new understanding, entering in contact with her experience from an embodied dimension. This allowed her not only to make the body map, but also to describe her experience in greater depth.

As a limitation of the use of body mapping, we can think of the difficulty of this method to represent *change*. The moments of a new understanding involved a change; a movement from one state to another. To depict the change through the body mapping, we chose to portray the states before and after the change in the body map. However, it might be interesting to explore the use of an expressive technique or method that allows to account for the features of the experience of the actual change. In more general terms, throughout the study we realized that expressive languages, such as the one used in the body mapping, is also subject to what, in phenomenological terms, has been called the “natural attitude”. Just as with verbal description, we can also relate to artistic languages from the perspective of our judgments, beliefs and preconceptions. As is the case with words, this may draw us away from our embodied experience. Therefore, the work of suspending our natural attitude, typical of a phenomenological approach and of first-person methods [66], is also necessary when using expressive or artistic languages. As a future line of methodological exploration, we can consider the inquiry into the question of how to promote this suspension of the natural attitude in the case of expressive languages. Would it be possible to outline guidelines to do this that can be transposed for different kinds of expressive languages?

Finally, it seems relevant to highlight that the combination of the three qualitative methodologies used in this study allowed for triangulation of data, providing reliability and transparency to our results. According to Okuda and Gómez-Restrepo [67], by using triangulation, we analyze the same phenomenon through different perspectives, which provides different types of information that are complementary and may be convergent, as the data in this study suggests

Conclusions

This study suggests that recovery for people with fibromyalgia involves a process of making sense of symptoms at the same time as dealing with important aspects of life. A key element within this process is the person gaining familiarity and becoming intimate with their sensations, feelings and desires, allowing them to generate a change in their relationship with themselves and with their disease. There was a consistency of results across the three methods of data collection used and at the same time a complementarity. Integrating the three methods allowed us to approach different aspects of the subjective experience of the participants, deepening understanding of the fibromyalgia recovery process.

Notes

Competing interests

The authors declare that they have no competing interests.

Attachments

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1. Attachment 1_jat000014.pdf (783 KB)
Supplementary material A: Semi-structured interviews
2. Attachment 2_jat000014.pdf (591 KB)
Supplementary material B: Micro-phenomenological interviews

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Corresponding author:

Dr. Camila Valenzuela-Moguillansky
Centro de Estudios Laboratorio de Fenomenología
Corporal, Camino segunda faja al Volcán, Villarrica, Chile
milamogui@gmail.com

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