Pain and Body Awareness

An Exploration of the Bodily Experience of Persons Suffering from Fibromyalgia

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> Context • Despite the fact that pain and body awareness are by definition subjective experiences, most studies assessing these phenomena and the relationship between them have done so from a "third-person" perspective, meaning that they have used methods whose aim is to try to objectify the phenomena under study. **> Problem** • This article assesses the question of what is the impact of a widespread chronic pain condition in the bodily experience of persons suffering from fibromyalgia. **> Method** • I used an interview methodology stemming from a phenomenological approach called the "elicitation interview." **> Results** • The results indicate that the intensification of fibromyalgia pain does in fact affect different aspects of body awareness: in particular, experienced body size, weight and localization, as well as the experience of owning one's own body. In addition, these disruptions in patient's body awareness have as a result, a modification of the experience of pain, leading to the apparently paradoxical experience of being in pain while not feeling it. **> Implications** • The elicitation interview approach made it possible to gather and analyze descriptions of the bodily experience of persons suffering from fibromyalgia. This approach allowed the consideration of the hypothesis that the disruption of implicit knowledge of the topography of patients' bodies prevents them from referring to the pain sensation in terms of its localization and intensity, transforming the sensation in a way that is experienced as paradoxical. Further studies should be conducted that focus on the interplay between attention, pain and body perception. **> Constructivist content** • The study presented in this article is framed within the perspective that the study of conscious phenomena should consider a first-person perspective, which is in line with constructivist approaches.
> Key words • **Pain, first-person approach, fibromyalgia, body awareness, elicitation interview, body perception.**

Introduction

Recent studies suggest a relationship between pain and different aspects of body awareness. For instance, patients suffering from complex regional pain syndrome (CRPS) and lower back pain present a disruption in the ability to rotate mentally the painful body part (Schwoebel et al. 2001; Schwoebel et al. 2002; Bray & Moseley 2010). This deficit has been linked to a disruption of the internal representation of our body in relation to movement or "body schema." Other studies have recorded reports by CRPS and lower back pain patients of the feeling that their painful body part does not belong to them (e.g., Galer, Butler & Jensen 1995; Galer & Jensen 1999; Förderreuther, Sailer & Straube 2004; Wand et al. 2009). There is also evidence that CRPS patients have difficulty locating their painful body part (Sumitani et al. 2007b; Lewis et al. 2010). In addition, brain imaging studies have provided evidence suggesting that chronic pain is related to an alteration of the location and size of areas on the primary somatosensory cortex that correspond to the representation of the affected body part (Flor et al. 1997; Maihöfner et al. 2003).

Moreover, other studies have shown that changes in various aspects of body awareness can modulate pain perception. For instance, Lorimer Moseley, Timothy Parsons and Charles Spence (2008) asked a group of chronic arm pain patients to evaluate the intensity of their pain after doing a set of standardized movements. When looking through magnifying or minifying binoculars, patients felt respectively more or less pain than when they looked directly at their arm. In addition, physically measured swollenness of the hand increased when patients looked through magnifying binoculars and decreased when they looked through minifying binoculars. The authors interpreted these results in terms of a bi-directional link between pain and body tissues on the one hand and the body image on the other. They proposed that the decrease in pain intensity while looking through minifying binoculars could be due to a reduced sense of ownership of the limb (for a review of the studies assessing the relationship between pain and body awareness, see Valenzuela-Moguillansky 2012a).

Taken together, these studies led to the hypothesis that the mechanisms underlying the internal representation of the body are involved in the chronicity of pathological pain (Harris 1999). Since then, several studies have assessed this hypothesis (e.g., McCabe et al. 2005; McCabe et al. 2007; Sumitani et al. 2007a). However, most of them have been conducted with patients suffering from chronic pain syndromes that involve local pain, such as CRPS and lower back pain. Very few studies have examined the relationship between body awareness and pain in widespread chronic pain syndromes such as fibromyalgia. Besides, despite the fact that pain and body awareness are by definition subjective experiences, most studies assess-

ing these phenomena and the relationship between them have done so from a "third-person" perspective, meaning that they have used methods whose aim is to try to objectify the phenomena under study. In the case of pain research, these methods have made it possible to gain valuable knowledge about the physiology of nociception and the neural processing of noxious stimuli. However, little is yet known about the relationship between these organic correlates and the experience of pain. This fact became very clear in studies on chronic pain conditions such as fibromyalgia or phantom limb pain, for which no organic cause has yet been found. In the clinical domain, the relevance of considering the subjective character of pain, or having a "first-person" perspective, is becoming increasingly evident. The physiological reference frame alone appears to be insufficient to understand chronic pain (Danziger 2010) and so the development of skills that aim to listen (Tamman 2007) and analyze patients' discourse (Charon 2006) have begun to be considered. The concern about the place of the lived experience in the scientific study of conscious phenomena is not limited to the clinical domain but is generally present today in the different disciplines involved in the study of consciousness. A growing group of researchers consider the inclusion of the lived experience an imperative in the study of conscious phenomena (e.g., Varela, Thompson & Rosch 1993; Varela 1996; Velmans 2000; Price, Barrell & Rainville 2002; Petitmengin, Navarro & Le Van Quyen 2007; Froese, Gould & Barrett A. 2011).

In this article, I present the results of a study that aimed to explore the bodily experience of persons suffering from fibromyalgia from a first-person perspective.

Fibromyalgia is a widespread chronic pain condition defined by the presence of long-lasting widespread muscular pain and the finding of at least 11 of 18 tender point sites on digital palpation. Other associated symptoms are fatigue and sleep disturbances (Wolfe et al. 2010; see Wolfe & Hauser 2011 for an up to-date discussion). Fibromyalgia has a prevalence in France of 1.6% and it is most commonly found in middle-aged women (Perrot et al. 2011).

In the first part of the article, I give a brief presentation of the methodology that I used to gather and analyze patients' descriptions. Then, I present the results of the analysis of seventeen interviews that explored the bodily experience of twelve patients throughout a particular moment of outstanding pain, which I will henceforth call the "pain crisis." The results provide a general characterization of the fibromyalgia pain and a characterization of the pain crisis in terms of its diachronic and synchronic structure. The results regarding the description of the pain crisis indicate that as pain increases, different aspects of the patients' body awareness are disrupted: in particular, experienced body size, weight and localization, as well as the experience of owning one's own body. In addition, these disruptions in patients' body awareness had as a result a modification of the experience of pain, leading to the apparently paradoxical experience of being in pain while not feeling it. The discussion concentrates on the latter experience and I consider the possibility that the disruption of implicit knowledge of the topography of patients' bodies prevents them from referring to the pain sensation in terms of its localization and intensity, transforming the sensation in a way that is experienced as paradoxical.

Method[1]

To characterize the impact of pain on the bodily experience of persons suffering from fibromyalgia, I used an interview methodology stemming from a phenomenological approach called the "elicitation interview"[2] (Vermersch 2011). The elicitation interview, first introduced by Pierre Vermersch and developed in the field of cognitive science by Claire Petitmengin (1999; 2006), is a technique that attempts to guide a person to recall a given experience, examine it and describe it with great precision. Originally designed to study the cognitive processes involved in learning, the technique was then incorporated into the neurophenomenological program proposed by Francisco Varela (1996) and since then has been used and tested by a growing number of researchers in the cognitive (e.g., Lutz et al. 2002), clinical (Petitmengin, Navarro & Le Van Quyen 2007), therapeutic (Katz 2011) and managerial (Remillieux 2009) fields.

The first step of an elicitation interview is to lead the interviewee to the evocation of a past experience. "Evocation" refers to recalling a given experience as if re-enacting it. This is achieved by first identifying a single experience and then asking about the sensory atmosphere of the moment, facilitating a description from an "embodied position" (Vermersch 2011). The state of evocation can be recognized by the extent to which the person is "in contact with" the experience that he or she is describing. A number of non-verbal, verbal and para-verbal signs have been identified that indicate the interviewee's level of connection with an experience (Hendricks 2009[3]; Vermersch 2011; Petitmengin 2006). Once the person is in a state of evocation, the actions (physical or mental actions) that the person performs throughout the specified situation are used as an axis of questioning (Vermersch 2011; Petitmengin 2006). We can then ask about the temporal evolution of the actions and establish an outline of their sequence, accessing what has been called the "diachronic dimension" of the experience. Depending on the research question, the diachronic dimension of the experience can be explored at different levels of detail. Thus, once a coarse sequence of events or actions is established, the interviewer may guide the interviewee to direct attention to finer levels of the experience. Using the sequence of actions as an axis, the qualitative aspects of the experience for a particular moment, or its "synchronic dimension," can then be explored. Usually interviewees glide into general descriptions of condensed situations that make it difficult to produce precise descriptions. Therefore it is important to

1| For a detailed description of the methodology for conducting and analyzing the interviews, see chapters 4 and 5 in Valenzuela-Moguillansky (2012b).

2| In French, the name of this technique is "Entretien d'explicitation." It was first translated to English as "explicitation interview." In 2013 it was agreed that the English translation would be "elicitation interview."

3| Marion Hendricks built the "experiencing scale" that measures the extent to which a person is in contact with his or her experience while describing it. The indicators Hendricks used to evaluate the level of contact with the experience are similar to the ones described here.

continually bring the interviewee back to the chosen particular situation.

The first step in the analysis is the transcription of the interview. After reading the interview, general anecdotal descriptions are set aside and all the information regarding the experience itself is selected. In this study, I then proceeded to identify events, generally interviewees' actions, that marked different stages or phases of the crisis, allowing the identification of the *diachronic structure* of a given patient's pain crisis. I then looked at the experiential categories that characterized each phase of the crisis, identifying the *synchronic structure* of each phase for a given patient. In this way I created an individual representation of the structure of the pain crisis. I repeated this procedure for each patient and then compared the individual structures, looking for invariants across different patients. Based on the invariants, I constructed the generic structure of the experience of a fibromyalgia pain crisis.

Results

Twelve people were interviewed (11 females, 1 male; mean age: 55.4 years). Five of them underwent two interviews, and three underwent three interviews; the others were interviewed once. A first series of interviews was conducted between June and July 2011, a second series of interviews in December 2011 and a final series of interviews in April 2012. Interviews were conducted in French; all the extracts of interviews reported in this article were translated into English by the author. The interviewees' identification codes are given in parentheses at the end of each quotation, as noted in Table 1. Questions from the interviewer and key parts of the descriptive statements are in italics.

Interviewee ID code	# of interviews	Gender	Age	Duration of the symptoms (years)	Duration of the diagnosis (years)
N.A.	2	Female	51	7	1
M.C.	2	Female	55	~10	8
N.D.	1	Female	50	No data available	11
E.J.	2	Female	43	7	6
F.F.	2	Female	64	31	11
F.V.	1	Female	73	7.5	4.5
I.Q.	3	Female	48	25	12
M.H.	1	Female	60	27	15
M.B.	1	Female	73	19	12
R.F.	3	Male	41	11	0.5
S.P.	1	Female	47	~32	7
Y.G.	1	Female	60	5	4

Table 1: Interviewee demographic.

General description of the pain

Before presenting the results of the analysis of the pain crisis, I will present an overview of the general description of the fibromyalgia pain and its impacts on the interviewees' lives.

Three main types of pain were identified in terms of localization, intensity, quality and frequency. The first type of pain is not so intense, but is constant and global, covering mainly the back of the head, neck, shoulders and back, giving its sufferers a feeling of heaviness and tiredness. Some interviewees refer to this as a layer of "background noise" pain. Second, over the background layer of pain, more intense and local pains, which could be present for periods of weeks or months, were described. They were generally located at the level of the buttocks, hips and legs, although other locations were also reported. Interviewees described these pains as compressing and contracting. The third type of pain, less commonly described, was a brief but very intense pain described as stabbing and paralyzing. In addition, six out of the twelve interviewees suffered from migraines and three from pain associated with irritable bowel syndrome.

When talking about the frequency and intensity of the pain, the interviewees described experiencing their bodies as constantly tired, heavy and painful. Moments of intense pain may occur throughout the day, according to different factors. One of the factors was the time of the day: mornings were usually a difficult moment, specifically the moment of waking and standing up (see Figure 1 and Box 1 for a description and an illustration respectively of the moment of waking up). Other situations that led to increased pain included physical effort, emotionally demanding situations and poor-quality sleep, among others. However, increases in pain and fatigue were generally unpredictable, a fact that the interviewees described as very frustrating. The frequency of episodes of very intense pain varied from one a day to one a week. These pain crises generally lasted a few hours. Most of the interviewees had been prescribed analgesics such as Ixprim, tricyclics such as Laroxyl and anxiolytics such

BOX 1: Description of the moment of waking up by the interviewee E.J.

Coming back from a shallow sleep

"Basically I wake up, I don't have the impression of waking up from a very deep sleep, I slept badly because I stayed at the surface [...] So it's not like consciousness comes to the surface from very, very deep down"

I feel the pain coming

"There's something really fetal in this, if I stay in this matrix here for the night, I won't go meet the pain as I'm anticipating it and I start to feel it and that, it goes on, it goes on, it goes on, [...] I try to move as little as possible, to stay in sort of the cradle of sleep"

The body feels electric

"The body is not rested, is not rested, there's something electric, like a sort of perception and that amplifies to waking consciousness, that all the nerve connections are on, they all light up, it's like it's an electric circuit that isn't, that doesn't work right, that's vibrating, there's a sort of vibration [...] it's really everywhere, unpleasant electrical stuff that's vibrating all over the place. So at once there's that sensation of exciting things, there's a kind of excitation of the skin, the muscles, the nerves [...] this sort of vibration and electricity is happening at the surface, on the body, that's it, there are really these two things, it's not deep, but it's really on, that's why I'm talking about excitation, it's happening on the skin, it's not far into the body, it's not deep."

At the same time the body feels heavy

"And at the same time there's this really strong heaviness [...] and at the same time one side of the body is totally exhausted, because it's not rested [...] and yeah, besides [the electric sensation] there's also a really heavy side, this part is very deep"

Conflict between staying still and standing up

"I just want to bury myself in bed and not come back out [...] I don't want to move [...] Because facing this pain is unbearable, so I don't want to feel it [...] I know that for this sensation of vibration, excitation that's unbearable, that's amplifying and becoming more and more pain, anyhow the more I wake up, the more painful it becomes, I know that the way it stops is when I move [...] and here I start to say to myself, there's my brain that's starting to wake up: I have to go work, I have to get up, but I don't want to wake up, I can't get up, I'll stay here another 5 minutes [...] I feel time passing and I let it do that and I try to buy as much time as possible and afterward in this sort of conflict [...] I try to continue on with my dreams, so still with the idea of staying there, of continuing the night, of staying in a place where the pain doesn't exist."

as Ravotril. Two of them had decided to stop taking medication completely due to its impact on their quality of life.

The impact of the pain on their daily lives was severe: most of the interviewees reported being unable to perform a full-time job and said that daily activities are highly affected by their condition. These included: traveling on public transport, being seated or standing for long periods, shopping for food, driving, sharing a meal with friends, going for a walk or having a sexual relationship.

Interviewees described some general aspects or a "global felt sense" of living with fibromyalgia that I considered very illustrative of their felt experience. One was the feeling of "slowing down" of the body. Interviewees described the feeling that their body had slowed down, as if their body would not obey them:

> "Everything goes in slow motion, everything is slowed down; that's it. This is the deep feeling I've always had, the slowing down of the body, which does not obey as desired because there is pain but also because there is not necessarily pain but it's tired so it goes slower." (M.H.)

They described incongruence between their intention to act and the actual possibility of acting:

> "The body doesn't respond to the commands you give, you know? You want to do something and the body says: Niet! No question, I cannot, I'm not going to do it, I can't. It is as if you wanted to change gears in a car, (…) and the car does not obey; that's an image, but I think, yes, I had never thought of that, but the body does not obey, that's it." (M.H.)

In addition to this slowing down of the body, the interviewees also described a slowing down of certain cognitive capacities. They described the feeling of thinking more slowly, of having difficulties concentrating and forming memories:

> "I'll maybe go to take [the medicine], but I won't take it … because I forgot in the meantime and in my mind I took them.
> *And what happens in between?*
> I don't know, I don't know … that, that happens to me sometimes, I go to do something because I'm not feeling well and then finally I don't do it, I don't know why." (Y.G.)

Probably related to the feeling of slowing down of the body, several interviewees described the feeling of being confined to their bodies, as if in a prison:

> "It's as if everything was locked, as if all of my joints were locked and I was caught inside, in fact kind of like imprisoned in a kind of body or an envelope that has locks inside it that I can't, that I can't, like doors that I can't open." (R.F.)

Another feeling that often appeared was the sensation of being "in parentheses," of being in a waiting or "pending" state:

> "In fibromyalgia you have a lot of this idea of waiting, as if you were in parentheses inside of something, it's really boring, in fact the parentheses are… we come back to the idea of the bars, we are in parentheses and it's a pain, pff!, you're constantly in parentheses, you see what I mean? That's what's really emerging as I talk to you today, I'm realizing how much we're in parentheses." (M.H.)

"Six years have passed and I didn't see them go by, I think there's a period where there's a hole in fact. For five years I can't go back and say, ah yes, this moment…, I don't know … I don't know, I can't place myself in time, I don't know what happened. I'm better on the year 2011, I think I'm more aware of what's happening, but before it's like a black hole, I don't know." (Y.G.)

"I really have the impression, there's a film I saw that's called 'The days where I don't exist' […] there are hours and days when I don't exist, my body exists, but I do nothing and I think of nothing, for me that expression speaks to me and in fact at the TCC[4] cognitive group that week, there was a woman who said the same thing, that she had the impression of having lost 5 years, and yeah, there are hours and days when that's how I feel it […] I'm stuck waiting, I don't know, like cosmonauts who spend years in hibernation" (I.Q.)

This global felt sense of "being in parentheses" appears to be very important since it seems to involve a metaphor for the perception of time. It also points to the perception of the body and space. The parentheses refer to a suspension of time but also to a feeling of being prisoners of their bodies and a limitation on their space of possible actions.

Generic structure of the pain crisis

The generic structure of the pain crisis was created by integrating the diachronic structure, or the temporal characterization of the crisis, with the synchronic structure, or qualitative characterization of the crisis at each stage.

It is important to highlight that the moments of outstanding pain or pain "crisis" unfold, like most of our experience, as a part of a continuum: they do not have a clear beginning or end, nor are they divided in a clear-cut fashion into different "phases." The phases are temporal delimitations of the experience whose aim is to allow the formulation of its general structure. That is why when trying to "cut up" the individual experiences in this way, it is difficult to establish a clear criterion on where to cut.[5]

Through the analysis of the interviews, six phases were identified as making up the diachronic structure of the pain crisis. Some interviewees described certain phases in more detail than others, and some concentrated their description on only one or two phases. The duration of each phase was not systematically assessed in the interview, but according to patients' descriptions, it is quite variable. In general, the passage from Phase 1 to Phase 2 was rapid and the duration of Phase 3 varied according to the particular situation.

Phase 0: "Before the pain is present"

This phase groups together patients' descriptions of what they were experiencing before the onset of the pain crisis. Pain already occurring in this phase was referred to as "background noise." Generally, this pain was of mild intensity and remained in the background of attention. Most of the interviewees described having been engaged in an activity before the crisis, with their focus of attention on the action that they were performing. Both pleasant and unpleasant bodily sensations were described in this phase. Fatigue and contraction were the most commonly described unpleasant bodily sensations. Some interviewees described the presence of an inner dialogue projecting the problems to come. Two interviewees described perceiving the first indications of the pain crisis at the moment of waking up. Already, in this phase they become aware of the imminence of a difficult situation. In these cases, they described feeling their bodies as blocked, as well as irritability. One of them said that the fact of being irritable had an impact on her body, wherein she felt it contracting and experienced "electric" sensations.

Phase 1: "Detection of the pain"

In this phase, pain intensified either due to an external event or to an endogenous increase, and began to occupy the interviewees' focus of attention. The appearance of the sensations occurred in some cases gradually and in some cases in a sudden manner. Pain was localized in specific body parts, usually the back, legs and hips. The pain was described as "heavy," "stabbing," "pushing" and "burning." Fatigue and contraction also increased in this phase. One interviewee described "electric" sensations and another an overall "relaxation." As shown in the following descriptive statement, the latter was described by an interviewee for whom the pain crisis was associated with the end of the activity:

"The pain arrives once you unwind […] I feel a loosening […] it's a loosening in the whole body and then abruptly there are these pains that appear in the neck and the back of the head" (F.F.)

In this phase, attention is still focused on the activity that was being performed but it initiates a reorientation of the focus of attention towards the bodily sensation. Depending on the dynamic of appearance of the bodily sensations, the reorientation of attention occurred either in a gradual or abrupt manner. Interviewees described becoming aware of the imminence of a pain crisis at a higher frequency than in the previous phase.

The emotions that were described in this phase are anguish, rage and irritation.

"I say to myself, I don't know how to express this. I'm sick of my body, I always say to myself that if only I could drop it off somewhere and continue to live [laughs]. It's, I'm angry at it, at my body." (M.B.)

Regarding the behaviors there were:

1. In relation to pain: hiding the pain and using specific strategies in order to deal with the pain such as avoiding specific movements.

"Here I do like I usually do, that is, I completely cover over what's hurting me, I act as if I weren't in pain." (R.F.)

2. In relation to others: two interviewees described being irritable. Interestingly, one interviewee explained that he became aware of the presence of the pain by noting his own aggressive behavior.

4| Abbreviation of the French name for "Cognitive Behavioral Therapy" (Thérapie Cognitive Comportementale).

5| For a detailed description of the method and criteria for establishing each phase, see chapters 4 and 5 in Valenzuela-Moguillansky (2012b).

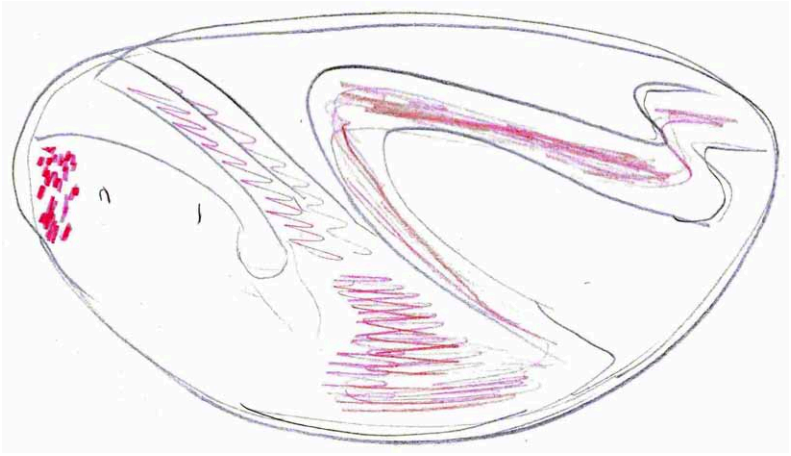

Figure 1: Illustration by E.J. of her pain: "that's my symbolic space, it's my bubble, I need to be inside that bubble [...] I'm both well and not well at the same time [...] I'm lying down and I'm inside that [she points to the bubble], in a world in fact that's protective."

"I must have started being very aggressive with the dogs, so shouting very loud for them to come back." (R.F.)

3. In relation to the activity: most of the interviewees continued with the activity that they had been performing.

In this phase, interviewees also described the presence of an inner dialogue. In some cases, the content of the inner dialogue involved the projection of the possible consequences of the bodily sensations; in other cases, it involved a "mental battle" with the pain; and in a third type of case, it was simply a comment on the sensations, usually negative.

"Anyway, I was apprehensive about what would come next (…) you say to yourself: I'm not going to be able to do it." (F.V.)

Phase 2: "Increase and expansion of the symptoms"

Rapidly the body "imposes" its presence; pain intensifies and expands throughout the body. In addition to the localization previously described, many interviewees indicated that in this phase, the pain was felt in the whole body. Among the adjectives that were used to describe the pain were "heavy," "pushing," "contracting," "burning," "stabbing" and "like needles." The bodily sensations most frequently associated with the pain were fatigue, heaviness, contraction, compression, oppression and the feeling that the body is blocked.

Some of the descriptions suggest an impact of the pain and associated bodily sensations on the interviewees' perception of their body size and weight. The body feels larger, thicker and heavier:

"It's as if there was both a heaviness, as if this part of my body was greater, I mean … greater in volume, that's what I wanted to say … anyway that's the image that comes to me, yes, bigger, as if this part of the back was, I don't know, like zoomed." (I.Q.)

And near space is perceived as smaller, as if it were shrinking:

"I feel a bit as if the space was restricted around me, as if it had diminished and I can hardly breathe, I feel oppressed." (N.A.)

"And I would say that it's weird, I'm more, that the space shrinks a little and that I'm bigger, yes … as if I was not on the same scale of what is around me" (I.Q.)

The following description illustrates how the particular way in which pain was felt – in this case as something that contracted and compressed – seems to have had a particular impact on the way that the body and the space around it were perceived and on the way that actions were carried out:

"[…] the stronger the sensations of pain are, the more you have the sensation of having a thick, heavy body […] it's like being pregnant. I don't know if you've ever been pregnant? You're fat, a little bit handicapped because you make clumsy movements, constrained movements and it's kind of the same when you have a painful body, you have the impression of being voluminous, having a sort of amplitude in your gestures and your movements […] For example, when I'm in my bed and I'm in pain, I turn around to try and find a different position, but I have the impression that I'm a barrel, it's crazily hard to lean over; in comparison to how I was before it still really frustrates me." (M.C.)

The bodily sensations are in the focus of attention, and it becomes more and more difficult to concentrate on any activity; attention is constantly attracted by the bodily sensations.

"It [the pain] takes up the space […] it's hard to get away, to not think about it […] in fact that's it, in the car it's like the mind no longer keeps away the body's experiences." (E.J.)

In the following extract an interviewee describes how this capturing of the attention by the pain takes place:

"It seems to me that I start to be bothered at one spot and then at another and in fact all this information accumulates, well it's not that it accumulates, but it gets fatter in fact, there's this amount of information that's getting fatter, getting fatter, until I can no longer ignore it in fact, that I've got so many messages that are painful that arrive that I can't manage any more to just think about the conversation or that kind of thing." (I.Q.)

The reorientation of attention is associated with the awareness that the person is arriving at a limit:

"I become aware that the level is too high and so indeed, I shift my attention toward this painful information rather than… I don't switch, but the interest, I take less of an interest in my surroundings because I say to myself that if there's a, well I don't say it to myself, but I can't do anything else but lis-

ten to this painful information because there's too much of it." (I.Q.)

However, a redirection of attention toward the exterior (other people, activity, environment) can serve as a strategy and in some cases prevent the crisis from developing further.

Among the emotions that were described in this phase, the most common are rage and frustration. Other emotions that were also described were fear, exhaustion, lack of motivation, sadness, angriness and distress. Although exhaustion might be considered a bodily sensation, in these cases it seemed that exhaustion referred to the intensification of the fatigue to a point that it involves an emotional dimension.

"I sort of have the impression of a lead weight of fatigue and I feel that there's the morale side, because I'm not more tired before than after […] but I have an impression of exhaustion when this fatigue [pain] reappears." (M.B.)

Regarding the behaviors there were:

1. In relation to the pain: as in Phase 1, interviewees described hiding the pain, and implementing different strategies to deal with it. Among them, most were "resistance" strategies such as taking medicine, avoiding or performing specific movements, or attempting to direct their attention toward others.

"When you're with people, you take an interest in them, you talk, you ask questions, they tell me about their life, their kids, this, that, you don't think at all about your pain any more nor does it hurt, so … you lose your awareness of yourself and you project onto the other person's problems, their stories, school and all that, how are you doing." (F.V.)

But there were also a few descriptions of "passive" strategies such as allowing the pain to expand.

"Here I let go, I let go and the pain completely overruns [envahit] you […] Once the interest of what I was doing is gone, I let myself go and I come back to this pain that's there, that harasses you, that torments you, there you go, that's how I proceed." (F.F.)

A process of evaluation in some cases preceded the implementation of a given strategy. This process is composed of various operations, and its objective is to determine the type of pain that is present and to choose an appropriate strategy to implement.

2. In relation to others: as in Phase 1, aggressive behaviors were described.

3. In relation to the activity: most of the interviewees continued with the activity that they were performing but their performance was highly perturbed.

"Still, I've got the pain that's there, that bothers me as I walk, that bothers me as I climb the stairs, that prevents me from going fast, that prevents me from keeping my back straight, because at certain moments I put my hand like this on my back, well." (F.V.)

"I'm not able to keep up intellectually, physically." (R.F.)

The presence of an inner dialogue related to pain is less frequent than in the previous phase. As in Phase 1, the content of the inner dialogue involves the projection of the possible consequences of the bodily sensations, and it can also involve the evaluation of the possible strategies that the person will implement.

Phase 3: "Falling apart" ("Perdre ses moyens")

This phase corresponds to patients' description either of the interruption of their activity or of losing the ability to deal with the situation. This phase represents the peak of the crisis.

The intensity of the pain is described as unbearable, and the pain usually involves the whole body. Interviewees frequently described the pain as "burning," "stabbing" and "like being beaten." Less frequently, the pain was described as "having stiff/aching muscles [*courbatures*]," "like an electric current," as "compressing" and as "blocking."

The bodily sensations associated with pain were exhaustion, contraction and the feeling that the body was heavy. In addition, one interviewee described experiencing a feeling of numbness in his painful body parts. Interestingly, he said that at some point the pain was so strong that he could not feel his painful body parts any more – this feeling of numbness was thus experienced as a paradox:

"And that's the paradox, my legs, at a certain level of pain, they're so numb that I don't feel them any more, so in fact when I reach this level of numbness, I can really continue to walk, because I don't feel them anymore." (R.F.)

Two interviewees described an impression of foreignness regarding their painful body parts. In one patient, this impression was related to the feeling of numbness described just above. In the second patient, this was related to a change in the perception of size, shape and temperature, as described in the following statement:

"At that point, both of my hands were hurting a lot, I had the impression that they were very hot, red, swollen, enormous, and I felt that they were both like foreign to my body as if they were separate pieces, off to the side!!!!" (F.V.)

In addition, in this phase, descriptions of a hypersensitivity to touch, lights and sounds emerge as well:

"The light starts to bother me more and more and at a certain point it becomes unbearable and then sounds becomes unbearable too." (I.Q.)

Descriptions of a change in perceived body size are also present in this phase:

"Anyway that's the image that comes to me, yeah, bigger, that that part of the back was, I don't know, like zoomed-in, I don't know, I've never thought about this […] Yeah, so I don't know whether to describe it as a zoom or if it's like, in fact it doesn't hurt in one place, it hurts in a bunch of different places at the same place, well it's a bunch of little details in the same place that build on each other and so I receive more information from that area than from an area where it hurts less, that's maybe what I mean when I say that I have more information coming in from that area compared to normal." (I.Q.)

In this phase, the interviewees' attention was mainly captured by their bodily sensations.

"Now my attention was focused on the pain […] I pay attention to my breathing or else I'll focus on the place that hurts the most and I'll try to breathe through there, that's it, I'll do like that to get all the way to the car." (R.F.)

The impression of losing the agency of their actions and control of their body was also described:

"You've got your body that isn't responding so much any more, you're completely obliterated […] your body has a hard time responding […] your body no longer responds the way you would like it to." (N.D.)

As the name of this phase indicates, at this stage several interviewees described falling apart and becoming aware of reaching a limit beyond which they can no longer stand the pain and the whole situation.

"A sort of moment of becoming aware, of acceptance of the pain and my state, that I couldn't go, I couldn't keep on, I had to stop." (R.F.)

The emotions most frequently described in this phase were exhaustion, anger and distress. Other less frequent emotions were fear and frustration. In some cases, these emotions reinforced the bodily sensations, leading to a vicious circle that aggravated the situation.

Regarding the behaviors there were:

1. In relation to the pain: several interviewees described the implementation of resistance strategies. The most frequently described was the performance of breathing exercises: namely, directing the attention toward the breath in order to reduce the pain or integrating visualizations along with conscious breathing.

2. In relation to others: one interviewee described being aggressive.

3. In relation to the activity: at this stage, most of the interviewees interrupted the activity that they had been performing.

Inner dialogue: negative contents were commonly present when perceiving the increase and expansion of the pain. In some cases, this negative inner dialogue led to distress and to a further increase in pain.

"I said to myself, after all this effort to come to work, I get there and nothing works, and I broke down, I started crying, the pain got more powerful and I was really angry, because I thought: I made all this effort to get here and then I arrive at work and I can't work, so I was in a rage and then I really felt the pain building up inside me with my anger […] I became all paralyzed, in fact completely at a muscular level, all my muscles were knotted." (S.P.)

Phase 4: "Fading away"

This phase, identified in the descriptions of only one interviewee, is characterized by a state of "disembodiment"[6] in which, in addition to a disruption in the patient's body perception, there was disruption in the patient's perception of time and the feeling that her thought process had slowed down. As for the previous phase, in this phase there was also a transformation of the experience of pain.

The interviewee described two experiences after the peak of a crisis (as defined in the previous phase), in which she experienced her body and mind "fade away." She described being "knocked out" by the pain, clarifying that this state was different from falling asleep: she felt awake but not quite aware of what was happening, as if her mind had escaped into a state of "awake-unconsciousness." She lost the notion of time, feeling as if her brain had slowed down; she had fewer and fewer, and slower and slower, thoughts, and she just let them pass by. She described the feeling as like being in a state of "waiting"; she used the image of a cosmonaut, comparing it to the experience of floating, as if she were being carried away by the painful sensations. She also used the image of being in hibernation, as if she were suspended in a parenthesis, and as if she did not exist. The interviewee described feeling as if the boundaries of her body were blurred. She stated that she no longer "represented" her body. In her own words: "It's not really alive [the body], it's … yes, it's like a fog, like a solid fog" (see Figure 2). She also described the feeling of going away from her body, as if she no longer inhabited her body, as if she had withdrawn from her body, and said that she "stayed" somewhere, maybe in her head. She knew that she was in pain but she could no longer localize it. In this phase, she could not identify the location of the pain nor its intensity, and so it was, as she did not feel it.

It seems that in this phase, elements that were already present in the previous phase, such as the feeling of foreignness towards the painful body parts and the paradoxical experience of being in pain while not feeling it, intensify and expand to the whole body.

It is important to note that the identification of this phase, as different to the previous one, can be controversial. The fact that some of the elements that characterize it are already present in the previous phase, and the fact that is represented only in one case, can lead to the question of why consider it as a separate phase. I considered that, even though the disruption of body perception described in this phase could be considered as an extreme instance of a process that began in the previous phases, the presence of new elements, such as the disruption of the perception of time and the slowing down of the thought process, gave rise to a different phase. It could be argued that the patients' descriptions of feeling of foreignness towards the painful body parts and the experience of paradoxical pain categorized under Phase 3 correspond to Phase 4. However, as these patients did not spontaneously report a disruption in the perception of time or a slowing down of the thought process and as these issues were not explicitly asked about in the interviews, we cannot say that their state corresponds to that described for Phase 4. Certainly, the possibility that the feeling of foreignness towards the painful body parts and the experience of paradoxical pain is accompanied by a disruption in the perception of time and of the thought process should be further explored in a future study.

Phase 5: "Decrease in the pain"

This phase corresponds to patients' descriptions of the moment at which the pain and other bodily sensations began to decrease in intensity. Given that I posed fewer questions regarding this stage of the pain crisis, its description will be short and less analytical. In most cases, this phase involved resting, relaxing and the easing of the symptoms. In some cases, it involved re-engagement in an activity. However, this phase did not involve complete relief: the interview-

6| By the term "disembodiment" I refer to the experience of lacking a sense of being a body.

ees said that they remained physically and mentally affected by the crisis and that they could not perform their activities to their full capacity. For three of the interviewees, the crisis ended with falling asleep.

Conclusion

The objective of this study was to investigate the effect of pain on body awareness at an experiential level. More specifically, the aim was to investigate the impact of a widespread chronic pain condition such as fibromyalgia on patients' body awareness over the course of a moment of outstanding pain. With this purpose, I gathered and analyzed descriptions of a moment of outstanding pain from people suffering from fibromyalgia.

The results showed that various aspects of body awareness are affected in fibromyalgia patients, and that in the case of extreme changes of body awareness, pain perception is also affected. Although no generalization to the total population of fibromyalgia sufferers can be made given the small size of the sample, these results provide insights into how people with fibromyalgia experience their bodies. In addition, these results offer insights into the progressive changes in patients' body awareness as pain increases.

First of all, from the fibromyalgia patients' general description of their pain, I was able to observe that, aside from the pain crisis in which more dramatic changes in body awareness occur, they described the constant feeling of a tired and heavy body. Although these feelings are not disabling in the short term, they give rise to what might be called the "global felt sense" that characterizes the internal atmosphere of living with fibromyalgia. This global felt sense, which involves the "slowing down" of the body and the feeling of "being in parentheses," tell us not only of a change in fibromyalgia sufferers' bodily experience but also of a modification in the way that they experience their relationship with others: their painful body isolates them as if it were a barrier between them and the world. In Fuchs's (2005) terms, for fibromyalgia patients the body loses its "transparency." The body withdraws from its tacit position and presents itself explicitly, standing between the person's intentions to act and her actions as well as between her intentions to share and her emotional availability.

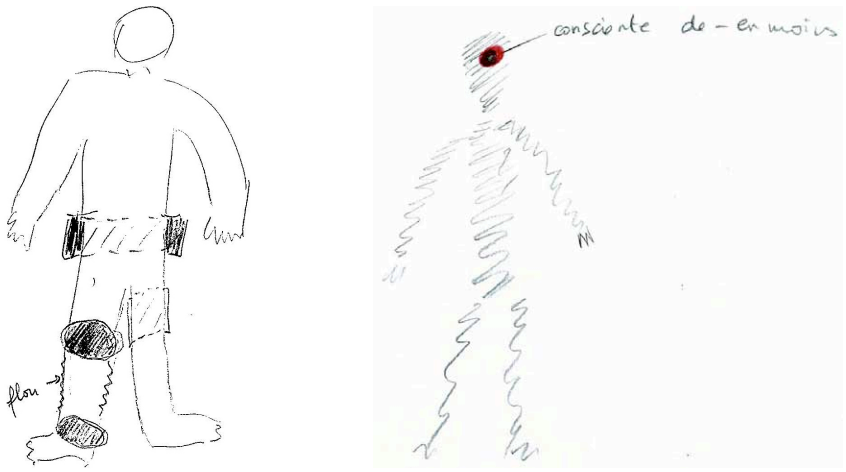

Figure 2: Illustration by I.Q. of her pain. The left-side drawing corresponds to the interviewee's pain in Phase 2 (Increase and expansion of the symptoms). The drawing on the right corresponds to the interviewee's pain in Phase 4 (Fading away). The dark parts in the drawing on the left indicate the locations of intense pain and the enhanced presence of those parts. The arrow indicates the parts of the body with less intense pain and is labeled with the word "flou" (blurred). In the drawing on the right, as the interviewee explained, the stroke of the pencil indicates that the whole body became blurred and that *she* was somewhere in her head (red circle), "conscious [of] less and less."

From the characterization of the changes in body awareness over the course of a pain crisis, the results suggest that as pain increases, attention is captured by the pain and by particular bodily sensations: the body becomes present in a heavy, contracted and compressed manner. Then, as pain expands throughout the body and its intensity continues to increase (Phases 2 and 3 of the pain crisis), some patients described changes in the perception of their body size, weight, posture and shape. In addition, some patients described a modification in their relationship with space: they felt their body become larger and felt as if space were shrinking. At the peak of the crisis (Phase 3), in which pain is unbearable, some patients described the impression that the painful body parts did not belong to them, expressing the paradoxical experience of being in extreme pain while not feeling it. Interestingly, this result suggests that over the course of a pain crisis, not only is there an impact of pain on body awareness, but there is also an impact of body awareness on pain. The description of one interviewee suggested the existence of a fourth phase in a very intense pain crisis. This phase broke with the previously observed relationship between pain intensity and body awareness: while in the previous phases increased pain was associated with increased awareness of the body and its limits, in this phase the boundaries of the body seemed to fade away. At this stage, the patient could no longer localize the pain nor evaluate its intensity. The patient said that in this state she experienced pain as an "intellectual" sensation. In the final phase of the crisis, pain and other bodily sensations decreased in intensity and interviewees slowly returned to their activities or fell asleep.

These results raise several interesting questions. In this discussion I would like to focus on that raised by the experience of *being in* pain while not *feeling it* described in Phases 3 and 4 of the pain crisis. How can we be in pain while not feeling it? As stated by

one of the patients, these experiences might be considered as a paradox.

Patients that described these experiences also described different types of disruptions in the perception of their bodies: the disruption in the perception of the size of the painful body parts, the disruption in the perception of space, the feeling that their painful body parts did not belong to them and, in a more extreme case, the loss of the sense of the patient's body boundaries. These patients also described the loss of the ability to localize their painful body parts and their pain. Taken together, these changes can be considered as a disruption in the patients' implicit knowledge of the topography of their bodies or in the so-called "body schema."

Behavioral and neural studies suggest that modifications in the body spatial reference frames have an impact on pain. Minoru Sumitani et al. (2007a) and Janet Bultitude & Robert Rafal (2010) showed that modifying the body's spatial reference frame using devices such as prisms and mirrors has an analgesic effect in CRPS patients. Along the same lines, Alberto Gallace et al. (2011) showed that having healthy subjects cross their hands over the midline of their bodies reduces the perceived intensity of nociceptive stimuli delivered to the hands. In a further study, Diana Torta et al. (2012) studied the neural correlates of the analgesic effects of crossing the hands. They showed that this effect was correlated with activity in the anterior cingulate cortex, the insula and the prefrontal cortex. In addition to the perception of pain, these areas are related to the network of brain regions which participate in the integration of multisensory information that underlies the representation of the body at both interoceptive and exteroceptive levels. The authors suggest that the analgesic effect of crossing the hands results from the conflict between different spatial frames of reference used to localize painful stimuli.

The above-mentioned studies show an analgesic effect of changing the persons' spatial reference frame. In the case of the fibromyalgia patients, the transformation of the sensation of pain did not involve analgesia or relief. It is important to note that these situations involve different types of changes in a person's body perception; the experiments mentioned above involve a "redrawing" of the body schema, in the sense that there is a change in the perceived location of the person's arm. The experiences described by the fibromyalgia patients did not involve a redrawing of the body schema but a "disruption," in the sense that, contrary to the experiment mentioned above, there was not a change in the perceived location of the person's body parts but an inability to locate them, as well as the loss of the sense of body ownership and the loss of the sense of body boundaries. Thus, in the case of fibromyalgia patients, there is not a conflict between different spatial reference frames used to localize painful stimuli but a loss of them. Pain is generally described and characterized in terms of its localization and intensity. It might be that the loss in the ability to localize the pain and to evaluate it in terms of intensity, as described by some of the patients, transforms the sensation in a way that patients can no longer refer to it and make sense of it as they generally do.

This hypothesis is in line with the observations presented by Pierre Bonnier (1905) more than a century ago in his studies on vertigo. Bonnier observed that patients who lose the ability to locate themselves in space experience strange illusions of depersonalization and disruption of the ability to identify objects around them. Bonnier suggested that it was the "sense of space" or the ability to localize that gives the "objective identity" to perceived objects as well as our subjective reference frame. In this sense he stated: "The sense of space defines the objective world for us, the non-self, by its properties of objective and subjective orientation." According to Bonnier, subjective orientation is "the perception of our position in relation to objectively oriented things in our environment, that of our posture, and our variations in positions and posture, that is, our own movements and displacements." It could be that the disruption in the ability to recognize the topography of our body has an impact on both the ability to recognize the body as one's own and the ability to identify the sensation of pain. Thus, maybe behind this apparent paradox there is a transformation of the experience of pain due to the disruption of the parameters that we normally use to characterize it. Interestingly, one of the definitions that the Oxford English Dictionary gives to paradox is "A statement or proposition which on the face of it seems self-contradictory, absurd, or at variance with common sense, though, on investigation or when explained, it may prove to be well-founded."

In other words, this analysis suggests first that pain is an experience that is intimately linked to the sense of the bodily self: the pain disturbs the sense of the bodily self and in turn, this disruption transforms the experience of pain. Furthermore, this analysis suggests that the history of sensorimotor interactions that allows the establishment of an individual's spatial reference frame underlies both the sense of the bodily self and the perception of pain.

These ideas are in agreement with the view that perception is an active process determined by sensorimotor contingencies. In terms of methodology, this study is framed within the perspective that the study of conscious phenomena should consider a first person perspective, which is also in line with constructivist approaches.

Further studies should be performed in order to investigate the interplay between the body's different frames of reference and the different ways in which pain can be experienced.

In addition, it would be interesting to investigate further the relationship between disembodiment, time perception and thought observed in Phase 4. Similar states have been described for different types of altered states of consciousness (e.g., Shanon 2002). In a recent study, Yochai Ataria and Yuval Neria (2013) report experiences of former prisoners of war in which they described that, while being in captivity, they experienced a state of disembodiment, a disruption of time perception and a disruption of their flux of thought. It seems relevant to compare these experiences, exploring the invariants of the conditions under which they emerged and investigating the implication of the relationship between embodiment, time perception and thought process on the constitution of the sense of self.

In summary, the elicitation interview approach made it possible to gather and analyze descriptions of the bodily experience of persons suffering from fibromyalgia. Patients described a constant feeling of a tired and heavy body. These feelings might give rise to the global felt sense of a "slow-

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ing down" of the body and the feeling of "being in parentheses." The results regarding the description of the pain crisis indicate that the intensification of fibromyalgia pain does in fact affect different aspects of body awareness, in particular experienced body size, weight and localization, as well as the experience of owning one's own body. In addition, these disruptions in patients' body awareness had as a result a modification of the experience of pain, leading to the apparently paradoxical experience of being in pain while not feeling it. I hypothesize that the disruption of implicit knowledge of the topography of patients' bodies prevents them from referring to the pain sensation in terms of its localization and intensity, transforming the sensation in a way that is experienced as paradoxical.

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