‘This really explains my case!’: biographical reconstruction of Japanese people with fibromyalgia meeting peers

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This really explains my case!: biographical reconstruction of Japanese people with fibromyalgia meeting peers

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ABSTRACT
Fibromyalgia (FM) is a controversial disorder with an unknown organic basis, so the legitimacy of the disease is controversial. People with FM struggle to explain their ‘invisible’ illness and to reconstruct their biographies. This study focuses on the significance of self-help groups (SHGs) in the process of reconstructing biographies of persons with FM. We interviewed 13 individuals with FM who participated in 2 different types of SHGs. Informants suffer from disparities between their severe bodily symptoms and appraisals from others, resulting in self-doubt and existential crisis. These disruptions were partially repaired by receiving a diagnosis, but this provided limited power to explain their ‘unreasonable’ disruption. Our findings indicate the importance of hearing the life stories of peers which can repair informants’ disrupted biographies through the fu-ni-ochiru experience, a form of comprehension of one’s illness by which the informant obtains a clear perspective through physical sensation, or full acceptance rather than logical understanding. Thus, our study expands knowledge regarding how people with FM reconstruct their biographies.

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Biographical reconstruction; Japan; fibromyalgia; self-help group; phenomenology; qualitative; sociology

Introduction
Fibromyalgia (FM) is a condition that leads to widespread pain throughout the body and a variety of concomitant symptoms. Diagnostic criteria for FM were devised in 1990 (Wolfe et al., 1990). Some studies suggest that abnormal function of the brain (central sensitisation or brain inflammation) is found in some FM patients (Desmeules et al., 2003), and recent studies indicate that glial cell activation and neuroinflammation are possible causes of chronic pain (Ji, Berta, & Nedergaard, 2013). However, the exact pathophysiological cause of FM is unknown, and no established treatment exists. Therefore, there is still controversy over the concept of FM. The primary trigger for this controversy is the ‘invisibility’ of FM (Barker, 2002); FM is not only visually inapparent, it currently lacks an aetiological explanation of physical causation. Empirical research has shown that FM...
receives little attention among physicians in comparison with other illnesses (Album & Westin, 2008), especially in Japan (Homma, Ishikawa, & Kiuchi, 2014).

In Japan, FM is called SENNI-KINTSU-SHO, but only 8% of lay persons have heard of it (Matsumoto, 2007). The diagnostic criteria devised by the American College of Rheumatology (Wolfe et al., 1990) is also applied in Japan. An FM Study Group for the Ministry of Health, Labour and Welfare was initiated in 2003, and their surveys are almost the only source of information about the situation of FM patients in Japan. An epidemiological study indicated a prevalence of FM similar to that in Europe and the USA (~1.6%), with an estimated 2 million potential patients. However, surveys indicated that only 32.2% of primary care physicians were familiar with the condition (Matsumoto, 2007). In comparison with the fact that most physicians overseas have long been aware of FM, awareness of FM in Japan has lagged markedly. Given such circumstances, Japanese patients with FM have difficulty seeking medical help for their condition, which results in their unusual predicament.

Because of these features, some patients have been stigmatised, for example, they are suspected of being lazy or pretending to be ill, in addition to the symptoms they suffer (Åsbring & Närvänén, 2002; Werner, Isaksen, & Malterud, 2004). These problems have been discussed in sociological research on patients with Medically Unexplained Symptoms (MUS). According to Nettleton (2006), three themes are evident in these studies: ‘living with uncertainty’; ‘issues of legitimacy’; and ‘resistance to psychological explanations of pain and suffering’. People with FM also face psycho-social problems, including a low quality of life and a high rate of suicidal ideation (Bernard, Prince, & Edsall, 2000). Thus, their suffering is existential in nature (Råheim & Håland, 2006).

As mentioned, because the complex suffering of FM patients is deeply rooted in a social context, exploratory studies from the patient’s point of view are crucial to understanding this suffering. A framework for studying the chronic illness experience is Bury’s concept of biographical disruption. According to Bury (1982), ‘chronic illness … is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted’ (p.169). Corbin and Strauss (1987) further defined three elements of one’s biography: (1) conceptions of self, (2) biographical time, and (3) body. According to Corbin and Strauss, this relationship, that is, ‘the BBC (biography, body, and conceptions of self) chain’ (Corbin & Strauss, 1987, p. 253), is disrupted in patients with a chronic illness. Charmaz (1983), who interviewed patients with various chronic illnesses, concluded that patients experienced a loss of self and have difficulty constructing a new self-image.

Conversely, there is a line of research that focuses on the re-interpretation of self or identity that occurs with illness, that is, the ‘work’ patients undergo to repair their disrupted biographies (Corbin & Strauss, 1985, 1987). The concept of ‘narrative reconstruction’ (Williams, 1984, p. 177) is helpful for understanding the situation in which reconstruction occurs. From interviews with arthritis patients, Williams emphasised the importance of talking about the ‘genesis’ of illness in such circumstances where the rupture between self and society leads to the reconstruction of self.

A few studies have focused specifically on the biographical reconstruction of people with FM, and these can be divided into two categories: studies that focus mainly on the reconstruction process itself, and those that focus on the resultant change in ways of living or the renewed meaning of illness. The reconstruction process does not progress
in a linear sequence as found in other patients with chronic disease. Madden and Sim (2006) describe patients’ conflicted feelings over the acceptance of an FM diagnosis. Such a non-linear reconstruction process is also reported in illnesses other than FM. For instance, people with traumatic spinal injury exhibit an analogous model of pendular reconstruction of self and identity (Yoshida, 1993), swinging back and forth between non-disabled and disabled aspects of self. As for the renewed self, Åsbring (2001) reported ‘illness gain’, the awareness of a new aspect of oneself that would not have been reached if the patient had not had the illness, although those phenomena differ greatly among individuals.

Past studies on reconstruction have focused on the areas already mentioned, but in recent years interest in the factors that facilitate biographical reconstruction has increased. Peer interaction has been found to play a major role in the identity repair of patients with conditions lacking a strong medical explanation, such as FM (Bulow & Hyden, 2003; Söderberg, Lundman, & Norberg, 1999; Steen & Haugli, 2001; Whitehead, 2006a). One setting for such interaction is the self-help group (SHG). Some recent studies mention the general function of SHG for patients with chronic illness, such as awareness raising or research promotion in a collective manner (Opava & Carlsson, 2012), or individual experiences such as finding positive meaning through interaction with other patients (Ide-Okochi, Yamazaki, Tadaka, Fujimura, & Kusunaga, 2013). The significance of SHGs for people with FM has been examined in terms of the role SHGs play in the creation of their collective identity (Barker, 2002), the experience of peer support (Juuso, Söderberg, Olsson, & Skär, 2014; Sallinen, Kukkurainen, & Peltokallio, 2011), and how patients in group therapy sessions for chronic pain were affected by discussions (Steihaug, Ahlsen, & Malterud, 2002). However, few studies have focused on the significance of SHGs for patients with FM from the perspective of biographical reconstruction.

The aims of the present study, therefore, were to explore and describe the meaning of attending an SHG and its contribution to reconstructing the biographies of persons with FM.

Methods
Theoretical perspective

This study was inspired by hermeneutic phenomenology, a method that is both descriptive and interpretive (van Manen, 1990, p. 35). Hermeneutic phenomenology tries not only to discover and describe the meaning of phenomena, but to interpret the meaning of phenomena as a lived experience. Phenomenological research is the study of lived experience. van Manen states that phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences. He also explains this using the term ‘life-world’, that is, the world as we immediately experience it pre-reflectively rather than as we conceptualise, categorise, or reflect on it (van Manen, 1990, p. 9). Phenomenological research tries to describe the experiential meanings we live as we live them.

The reason we adopted a hermeneutic phenomenology is that much of the suffering characteristics of persons with FM concern their lived experience. We comprehend the world through our body; hence, the world itself is perceived differently from the body with pain. The main task for people with FM is to seek to understand their own mysterious
disease and, thus, the researcher aims to interpret their situation from the perspective of those with FM. By focusing on the experience of SHG participation, we do not observe and measure the outcome that is set by the researcher; rather, we try to understand the experience from the viewpoint of the participants.

**Sampling and recruitment of informants**

Informants in the study were participants in either of two kinds of SHG meetings: a Chronic Disease Self-Management Program (CDSMP) or the Japan Fibromyalgia Support Association (JFSA). The CDSMP was developed at Stanford University, and includes participants with different diseases. The program is conducted by trained lay facilitators with chronic conditions. The CDSMP emphasises participants’ interaction, discussion and role modelling, which are the primary elements of SHGs.

To recruit informants with FM, we employed purposeful sampling (Creswell, 2007). The inclusion criteria were as follows: diagnosed with FM by a physician; physical condition tolerable enough to participate in interviews; and aged 20 years or older. We recruited informants through the Japan Chronic Disease Self-Management Association and JFSA by mail. Among the 14 CDSMP respondents who reported having FM in a questionnaire survey, 7 agreed to participate in the interview. One of these seven was excluded because she was the mother of a woman with FM. Ten JFSA members who had participated in member meetings were randomly selected by JFSA. Among those, seven members agreed to be interviewed. Therefore, we used 13 informants’ narratives for analysis.

**Demographic information**

Of the 13 informants, 11 were women and 2 were men, with a median age of 46 years (range: 29–73). Median time since the onset of illness to FM diagnosis was 6 years (range: 0.3–63). Nine informants had co-morbidities (chronic fatigue syndrome, irritable bowel syndrome, Sjögren’s syndrome, or Parkinson’s disease). Five informants were paid workers, although four of them worked at home. Four other informants were housewives, two were unemployed, one was a university student, and one was retired. Six people retired from previous work because of their illness. Five informants participated in both the CDSMP and JFSA meetings. There was no therapeutic relationship between the researcher and informants, nor was there prior acquaintance.

**Data collection**

In-depth interviews were conducted by the first author from August 2008 to October 2009. The interviewer, who has a chronic medical condition and is not a medical professional, began the interviews with a self-introduction intended to build rapport. The interview topics were (among others) the process until diagnosed with FM, difficulties before and after diagnosis, the reason for participating in an SHG, the experience in SHGs, and views about illness. On average, interviews lasted 133.8 min (range: 90–190). Interviews were conducted in the informants’ homes, community health centres or university
lecture rooms, at the informants’ request. Interviews were recorded on a digital audio recorder and transcribed verbatim with the consent of the informants.

The aim of the study was explained in advance to the informants through written material, and privacy protection and the right to withdraw were explained on the day of the interview. All informants provided written consent. All interviews were conducted in a private room to protect the informants’ privacy. This study was approved by the Research Ethics Committee of the Graduate School of Medicine at The University of Tokyo.

Data analysis

In general, hermeneutic-phenomenological analysis consists of naïve understanding, structural analysis, and comprehensive understanding. Råheim and Håland (2006) explain the analytical process by presenting five steps of analysis, which we have largely followed for the analysis of interview text.

Step 1: General impression. First, we listened to the interview tape several times and made a verbatim transcription. Then we read the interview text to grasp the meaning of the text as a whole, writing down general impressions. This process is generally referred to as naïve reading, in which the researcher reads the text in a natural attitude and interprets the essential meaning of the text.

Step 2: Identifying the main themes and subthemes for each interview. The text was divided into meaning units, treating each unit as equally significant. Next, we labelled each meaning unit with an in vivo code to create condensed meaning units. Next, we created subthemes from the condensed meaning units. Theme is a thread of meaning that penetrates text parts. Subthemes were then synthesised into main themes, thus increasing the level of abstraction. During the entire process, we wrote down the possibility of other interpretations and sought advice from other researchers.

Step 3: Synthesis of main themes and subthemes across interviews. We compared the main themes generated by all informants to describe the structure and relationship between those main themes. The main themes were created by subthemes from a single interview or across interviews.

Step 4: Developing typologies. The experiences of people with FM were classified into two typologies: Various aspects of disruption, and Meaning of meeting peers.

Step 5: Interpretation of lived experience comprehensively. Generated themes were considered in relation to the research question again, and the text was reread as a whole for a general impression (naïve understanding) with as open a mind as possible. Because we cannot eliminate our pre-understandings completely, it is important to read the text with an awareness of them.

Findings

Table 1 presents main themes and subthemes developed through the analytic process. First, we briefly describe the ‘Various aspects of disruption’ experienced by informants, before noting their SHG experiences. We then refer to the ‘Meaning of meeting peers’, which consisted of five main themes.
Various aspects of disruption

Most of the informants recounted first-hand experiences of bodily suffering such as somatic pain, fatigue and sleeplessness, and its severity. They had a strong desire for other people to recognise their predicament. Despite this, informants conveyed that other people, such as healthcare personnel, family and colleagues, failed to understand their situation. These situations included problems such as a lack of a legitimate medical explanation, scepticism of the condition’s existence, and failure to receive sympathy given the commonness of one’s symptoms. As a result of repeated criticism from others, some informants were confused as to whether their physical senses were distorted. They tried to explain the cause of their symptoms using medical language or various lay explanations to understand their chaotic situation. The informants’ sense of isolation extended beyond their personal relationships, and developed into the feeling that society had no place for them. When this sense of alienation was compounded by a disruption in one’s personal life, for example, divorce or being laid off, informants felt hopeless. In other words, informants experienced an existential crisis in which they wondered if there was a point in continuing to live, given that they were unable to do anything because of their pain. In fact, eight informants spontaneously mentioned that they had attempted suicide or had suicidal thoughts.

For informants facing the scepticism of others, the identification of their illness was the first way for them to confront their illness. For them, having a name for their illness was the starting point of reconstruction, in that diagnosis provided an ‘identity card’, which made their condition recognisable. However, reconstruction does not necessarily proceed in a linear fashion. Even after one’s illness was identified, disruption could occur again based on the realisation of how FM is viewed by society. Because FM is a controversial and not widely known disease, informants are unable to explain it to others despite being diagnosed. In addition, many became depressed when they learn that there is no cure for FM.

Meaning of meeting peers

By receiving the diagnosis, informants were partially freed from the aforementioned disruptions caused by an ambiguous diagnosis and were spurred on to confront their condition, but they also began to want to understand what was happening to them.

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<th>Table 1. Example of themes.</th>
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Without the disease name, I couldn’t really tackle the disease, and push my way through it. Like questioning ‘who am I?’ or ‘where does this pain come from?’ (Wakako)

The main reasons why informants decided to join the SHGs were that, for example, they wanted to learn about the condition of other patients or why they developed FM, and they wanted to communicate with others. Above all, the predicaments of the participants were so severe that they felt driven to try anything available to them. These motivations were not very different between participants in the FM patient support group (JFSA) and the chronic condition management programs (CDSMPs).

I joined the JFSA in an act of desperation … I wanted to try everything which seems to be good in any sense, although I couldn’t imagine the contents of the workshop from the leaflet. The reason why I participated in the CDSMP workshop was that I, as an FM patient, was recognized as such by others at the JFSA meeting, which gave me … something like permission. (Chika)

Relativised view of self through relationship with others
Both members of the FM patient support group and participants in the CDSMP reported developing a conceptual scale to determine their place in comparison with others. For instance, in these SHGs, informants identified a positive individual as a role model who lifted their spirits. In other cases, informants who were still in relatively good health felt encouraged by encountering someone in a more difficult situation.

Knowing others helps me realize that my case is not so serious. … But, when I am alone, I tend to think that I can never bear this. Seeing others helps me view myself relatively and gives me some comparisons to see where I am. (Kanae)

Listening to the life stories of others produced changes in one’s interpretations, for example, an appreciation of the vast range of experiences in the world or the realisation that one’s problems were only one of many.

I examined my own illness not by looking only at myself but through contact with various patients and I probably discovered some things about myself by viewing my illness relatively. (Akiko)

Coherent explanation of what is happening
Members of an FM patient support group (JFSA) mentioned particular comfort and sympathy produced by the environment; namely, fellow members who have the same diagnosis understood their pain, which other people failed to understand. Although they had previously been isolated, attendees received emotional support by realising there was a place for them and that they were not alone.

[In the patient group meetings] we can share common sufferings: they are not always exactly the same though. We understand each other’s suffering, which cannot be understood by others. (Minayo)

Some informants continued to be suspected by others in their lives of being ‘lazy’, even after they were diagnosed, but by meeting people who had experienced similar situations, these informants realised they were not incorrect in their perceptions and they gained confidence in the reality of their experiences.
I was alone until now … there’s no one to understand me. I think it’s quite late already, in my 70s, but I’d like to communicate with others. Then I can listen to the prognosis of other people and agree with ‘it also applies to me’. So we can talk based on the common topics. Of course I wanted some information, but more I wanted communication. (Rumi)

By sharing narratives, informants learned about difficulties experienced by other people with FM. They recounted comprehending why they were unable to get an accurate diagnosis. They became aware of personal characteristics, such as perfectionism or an overactive lifestyle, which are mentioned as background factors of FM. They also realised that other people with FM lead lives similar to their own. In other words, they felt it had been explained to some extent why they, and not others, had developed FM. This is the experience of coherently comprehending the events before and after developing FM, in Japanese fu-ni-ochiru (literally meaning ‘settle down in one’s belly’). In Japan, ‘belly’ is a metaphor for an important part of one’s mind, just as the heart is in Western culture.

Hearing that many of us tend to be stoic about things, I thought that ‘this really explains my case’. It was not work or my husband that caused this problem, but it was rather a natural occurrence. I realized that it was a matter of chance for me to get this problem, rather than wondering ‘why did this happen to me?’ I understood well. (Minayo)

These life stories of other people led to a change in the interpretation of one’s own illness, leading to a new perception that FM had perhaps not unreasonably disrupted one’s life. Before this awakening experience, having FM only meant that informants no longer led the daily life they had led before, with the life plans they had held before FM then abandoned. In other words, having FM was seen as a meaningless, fragmented incident in the informant’s own biography. Through accessing peer stories, one could then look back and experience the connection between oneself prior to developing FM and one’s current self. That is, informants received a somewhat more consistent explanation of their illness. Thus the fu-ni-ochiru sensation was a comprehension, but at the same time it had the implication of permitting a letting go of the obsessive drive to make other people understand their suffering. Thus, informants came to interpret having FM as a ‘natural occurrence’.

Recognition of the beneficial experiences relating FM and SHG participation

A change in attitude and interest levels occurred as informants realised the importance of meeting others after they developed FM. Some informants realised that meeting peers was in itself a beneficial aspect of having the illness. One informant stated:

Of course, it would be best if I had not had this illness. But there are people who I would not have met, there are other diseases or patients’ feelings, which would not have been known, had I not gotten FM. When I came to think that I am aware of those things ‘only because’ I got sick. So naturally, I think it’s all right that I got sick. (Akiko)

These shifts in focus led informants to have a new point of view; for example, they wanted to interact more with society and people. Informants often recounted that having suffered made them keenly aware of the perspective of someone else who is disabled or ill. Meeting individuals in difficult situations at the SHG led informants to want to be of help to others experiencing difficulties.
Having an illness has really made a lot of things more apparent. Like the hell that people with an illness go through. People who are really healthy don’t understand what it’s like to go through physical hardship first hand. … I’m better able to empathize with how tough it really is. (Minayo)

This view of vulnerable individuals expanded to include not just those with FM. Informants often recounted that having suffered made them keenly aware of the perspective of the weak in general. By meeting peers, informants felt other people’s difficulties ‘first hand’ and ‘from the bottom of their heart’, which helped them comprehend intersubjectively other people’s predicaments.

Of course, not all of the informants had a positive experience in SHG. Some (e.g. older people, informants who already had firm support from religion, and those who considered their condition to be mild) expressed sentiments such as the wish to be among healthy people rather than only meeting people with illness.

**Ability to conduct oneself irrespective of others’ evaluation**

A change in behaviour occurred, including not wanting to force other people, such as one’s family, to understand their condition. This does not mean that informants gave up on communicating, but rather they realised their anxieties were not special. Informants reached this stance through listening to accounts from people with various perspectives. This provided them the latitude to look at things from their family’s perspective.

[Family] aren’t the ones involved, so they don’t necessarily understand our pain. They don’t necessarily understand our suffering. In the end, there’s no way family can feel and comprehend our illness. If we understand that fact, we wouldn’t ask so much of them. (Akiko)

Previously, informants cared too much about other people’s views and feared criticism, including from healthcare personnel, and thus were unable to behave as they wished. The informants came to talk openly about their suffering or came to rely on people, not by pushing other people to understand their sufferings but by informing them honestly about their situation. Thus, informants no longer remained evasive; they realised there was no harm in telling someone they could not do something. This was a communication based on trust in others.

I wanted to try somehow to have other people understand all the pain and suffering I’ve been dealing with. If I was told I had appeared healthy until now, I had replied ‘uh, thanks’, but now [I reply] ‘well, I wasn’t’. (Chika)

**Renewed self-image**

Previously, informants considered pain to be the principal source of their suffering and wanted it eliminated. However, based on the experiences described thus far, these informants came to view pain as evidence that they were still alive. Three participants mentioned their view of pain as their body’s signal of a problem, such as fatigue, and sought to heed that signal.

Since the very first, I thought if only I wasn’t in pain. Nothing would be better. But now, I think I’m ahead of the game just by being alive. I came to see being in pain as proof that I’m alive. Pain is my friend. (Wakako)
Pain was no longer an enemy that should be hated, but took on a new meaning, such as a ‘message from the body’ as a part of the self. One informant stated that he procured this integrated image of body with pain and his self through meeting various people in the SHG:

As I’ve met a real variety of people, I’ve thought this illness is going to be with me for 50 years or so. There’s nothing I can do while I’m still alive. But I’ve come to think of it as some ‘proof’ that I’m still alive. (Takahiro)

**Discussion**

**Biographical disruption and the meaning of diagnosis**

A growing number of qualitative studies worldwide have described the illness experience of patients with FM (McMahon, Murray, & Simpson, 2012; Sim & Madden, 2008). The current findings reveal that Japanese people with FM experience similar disruptions in their lives. They experience the ‘double burden’ that Juuso, Skar, Olsson, and Söderberg (2011) mentioned: that is, patients live with pain and have to face doubt from others. In addition, there are quite a few articles that deal with identity issues among people with FM. Madden and Sim (2015) defined diagnosis as an interactive process between patient and doctor and pointed out that lay understandings or culturally desirable ways of help-seeking influence this negotiation process. Barker (2002, 2005) emphasised the way collective identity is formed in the context of a contested illness like FM; as the patients face public doubt, they fall into self-doubt and begin to question their own sanity. Barker has argued that this is the springboard for the vast self-help and support community. These are common features observed in our Japanese participants. However, in Japan, gaining diagnosis appears to have a more individual meaning when compared with the US examples, which has more political orientation.

Eight of thirteen informants recounted suicidal thoughts, and some had attempted suicide; these informants suffered a loss of the meaning of life. This existential crisis of our informants did not arise only from meaninglessness; rather, the crisis came from the experience of their bodily sensations and their legitimacy being denied, and their being treated as morally suspicious persons, which hurt their human dignity (Söderberg et al., 1999).

Identification of one’s illness is the first step towards the reconstruction of one’s biography (Madden & Sim, 2006; Whitehead, 2006b), and naming the illness is the categorisation of patients’ complaints and authorisation of these complaints (Brown, 1995; Jutel & Nettleton, 2011). Hence, when patients are given a diagnosis of FM, it proves at least that they are not malingerers. Ultimately, however, the diagnosis is socially meaningless, and patients return to their negative outlook over the long term (Madden & Sim, 2006; Undeland & Malterud, 2007). For this reason, Madden and Sim (2006) termed FM an ‘empty diagnosis’. Thus, being diagnosed with FM is not sufficient enough to repair patients’ disrupted biographies, especially the rupture between the body, self, and society. Nor does the diagnosis provide the answer to the simple but existential questions such as ‘Why me? Why now?’ (Bury, 1991). Unless patients are given an explanation for such questions, reconstruction of their biographies will be unsuccessful.
Experience of fu-ni-ochiru: the physical sensation of connection between past and present

The significance of attending an SHG stems primarily from helping informants construct an explanatory narrative while they are trying to understand why they have developed their condition. Among the narratives presented by members of the FM patient support group, ‘coherent explanation of what is happening’ was an area of note: specifically, the fu-ni-ochiru experience of why they developed FM. This phenomenon consists of several dimensions:

- Formation of causal explanations for FM
- Comprehension through bodily sensations
- Knowledge formed through peer exchanges.

Thus, the fu-ni-ochiru experience helps repair one’s disrupted biography.

First, regarding the formation of causal explanations, by listening to the life stories of one’s peers, the informant’s life prior to becoming ill, such as one’s character and circumstances, which previously were considered to be fragmented and meaningless, took on meaning. Williams (1984) found, based on interviews with arthritis patients, that narratives about the cause of illness are important facilitators to reconstruct the ruptures between body, self, and world. Here, ‘cause’ does not refer to the aetiology in biomedical terms, but instead to a personal rationale for ‘Why me? Why now?’ (Bury, 1991). Lay explanations of the cause of the illness, such as stress or overwork, are important in that they create a link between illness and life events (Blaxter, 1983). It is an attempt to find meaning, and to connect between fragmented past events and the present self with pain. In our SHG participants, we found that their narrative about the ‘cause’ was not mere lay explanation about aetiology, but the re-interpretation of one’s world view, the moment at which to place their fragmented life events into their biography.

Second, fu-ni-ochiru is a method of comprehension through bodily sensations. Here, the Japanese expression fu-ni-ochiru refers to a form of comprehension by which the subject obtains a clear perspective through physical sensation or full acceptance rather than simply logical understanding. Kitagawa (2002) states, “meaning” is fundamentally based on experience, so it is a form of existence. Thus, comprehension of meaning is an experience similar to an ‘aha!’ moment in which the person finds that something suddenly makes sense. Based on this awakening experience, people can live and communicate with others. Informants’ fu-ni-ochiru experience in our study would be experienced in the social context of a Japanese-language speaker in its exact sense.

However, the bodily feeling of comprehension and connection might be common phenomena in locations other than Japan. This bodily feeling of comprehension and connection might be close to the Williams (1984) concept of narrative reconstruction mentioned earlier. Steen and Haugli (2001) mentioned the importance of reappraising one’s body in their chronic pain treatment program. According to these authors, the central concept of the program is using the body as a ‘talking subject’, rather than ‘good’ advice or ‘right’ answers from health personnel. Here, the program’s role as a ‘room’ for exchange and the presence of peers was emphasised more than the program content. The participants commented on the merit of the program using existential terms, for example, ‘I have an increased awareness of who I am, I have discovered that things in me are interrelated – the way I behave, my body, my pain’. This kind of
process, in which patients re-interpret their pain and body as the reference points (Williams, 1984) for reconstructing the self, is similar to the experience of the informants in the current study.

As Kelly and Field (1996) keenly pointed out, there has been an understatement of the body in the field of medical sociology. For them, the body itself is the central link between self-identity and society. If this is true, we might say that the fragmented biography caused by the illness can be repaired by bodily experiences. Because such experience is not readily provided by physicians, peer exchanges among patients are particularly important.

Third, informants’ experience of fu-ni-ochiru was that of knowledge formed through peer exchanges. Attending an SHG contributed to reconstruction with regard to personal views of one’s body and the interpretations of pain. Of course, the reconstruction process is not a linear one (Yoshida, 1993), but for some informants, the third of Bury’s stages, ‘response to disruption’, seemed to begin.

The significance of meeting peers with FM, according to Söderberg et al. (1999), lies in it helping patients to construct their own explanation of their FM, hence leading to them maintaining their dignity. We can say that our fu-ni-ochiru experience represents the moment of repair of the self on such an existential level. In a vague diagnosis such as FM, SHG meet the needs for togetherness, confirmation, and information that healthcare personnel cannot satisfy (Juuso et al., 2014). Especially when considering the scant interest shown toward FM in Japan, simply exchanging information or a feeling of being accepted would be helpful.

The fu-ni-ochiru experience may have many parallels with feelings of revelation and dispositional understanding that can be found in different cultures and contexts; for instance, in other explorations of getting a diagnosis, or in the case of adults diagnosed with High Functioning Autism in later life. Apart from the experience, English has similar phrases (i.e. ‘feeling something in one’s belly/gut’) that appear very close in both language and quality of experience we described.

The current study provided interesting findings regarding the repair of one’s biography following diagnosis of illness. Meeting one’s peers with the same diagnosis does not simply provide general information; it also helps to repair an individual’s biography through knowledge based on bodily experience and the comprehension of one’s illness.

Limitations, strengths, and implications

This study has several limitations. First, we only interviewed people who were attending SHG meetings. Therefore, we should be careful in applying the study findings to people with FM who are not able to attend SHG meetings, including because of difficulty with their physical condition. Also, we cannot readily apply our findings to people who participate in different kinds of SHGs. However, when we reviewed the recent qualitative studies on FM patients’ experience of SHGs, we did observe numerous commonalities (Juuso et al., 2014; Sallinen et al., 2011).

Second, this is a study with a small purposive sample, as is usual in phenomenological studies. To ensure the rigour of naturalistic inquiry and its trustworthiness, we referred to the criteria of Guba (1981). For instance, to assure the credibility of our interpretations, we discussed with other researchers (peer debriefing) and obtained feedback on the data analysis from informants who agreed to provide advice (member checks). To enable the
transferability of the research findings, we attempted to describe the research context in detail (*thick description*).

Third, the researchers’ background may have affected our study findings. For instance, the interviewer is a patient with a chronic medical condition, not a medical professional. Therefore, it is possible that the researcher interpreted informants’ narratives using the terms derived from personal illness experiences. We cannot completely eliminate our pre-understandings; rather, in a hermeneutic-phenomenological analysis, it is important to make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories (van Manen, 1990, p. 47).

Although the current study has limitations, it contributes to illuminating the illness experience within the context of an understudied group. We interviewed participants from two different SHGs, which makes our findings applicable to the types of SHG in which FM patients are likely to participate. In addition, we did not focus on the contents or programs of SHG meetings, but on the meaning of meeting peers. Our study adds useful findings regarding how patients repair their disrupted biographies.

**Conclusion**

This study adds to the literature on how people with FM repair their disrupted biographies. Informants suffer from ‘invisible’ physically severe symptoms, yet with few abnormalities in medical examinations. When this is combined with suspicious views from others, informants begin to doubt whether their senses are normal. They fall into existential crisis and some experience suicidal ideation. By receiving the diagnosis of FM, their unstable identity or disrupted biography is partially repaired, but is far from perfect. There still remain the questions ‘Why me? Why now?’; to repair their disrupted biography, they need a personal rationale other than biomedical causal explanations.

SHGs helped informants to re-interpret their biographies through contact with and talking to other patients. Meeting peers who have the same disease, they recognise that their senses are normal and feel that they are understood. In the interaction between peers, hearing not only objective information but also the life stories of peers is crucial. By listening to these stories, individuals are able to reorganise the fragmented past events such as ‘perfectionism’ or ‘overwork’ into the narrative of illness causation. This reorganisation occurs not through a logical understanding but through the physical awakening or full comprehension of the *fu-ni-ochiru* experience. This embodied knowledge provides informants with a causal explanation for why they developed FM, which helps to repair the disrupted link between self, body, and society. This process then leads informants to re-interpret FM as a ‘natural occurrence’ in their life, through which informants feel freed from their previously obsessive drive to make other people understand and recognise their suffering.

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