

## EMPIRICAL STUDIES

**Living with a double burden: Meanings of pain for women with fibromyalgia**

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**Abstract**

Living with fibromyalgia (FM) means living with a chronic pain condition that greatly influences daily life. The majority of people with FM are middle-aged women. The aim of this study was to elucidate meanings of pain for women with FM. Fifteen women with FM were interviewed about their pain experiences and a phenomenological hermeneutic interpretation was used to analyse the interview texts. The findings show that meanings of pain for women with FM can be understood as living with a double burden; living with an aggressive, unpredictable pain and being doubted by others in relation to the invisible pain. The ever-present pain was described as unbearable, overwhelming, and dominated the women's whole existence. Nevertheless, all the women tried to normalize life by doing daily chores in an attempt to alleviate the pain. In order to support the women's needs and help them to feel well despite their pain, it is important that nurses and health care personnel acknowledge and understand women with FM and their pain experiences.

**Key words:** *Fibromyalgia, lived experience, pain, women, phenomenological hermeneutics*

*(Accepted: 20 June 2011; Published: 13 July 2011)*

Living with fibromyalgia (FM) means living with a chronic pain condition. Fibromyalgia has a considerable impact on daily life and several studies (Arnold et al., 2008; Cudney, Butler, Weinert, & Sullivan, 2002; Henriksson, 1995a, 1995b; Lempp, Hatch, Carville, & Choy, 2009; Råheim & Håland, 2006; Schaefer, 2005; Söderberg & Lundman, 2001; Söderberg, Lundman, & Norberg, 1999; Söderberg & Norberg, 1995) have shown that family, social, and working life are affected and restricted. Despite the great impact on daily life, previous studies (Madden & Sim, 2006; Undeland & Malterud, 2007) have shown that it is hard to legitimise the illness experience of FM and the diagnosis is not helpful for the people who have it. According to Rodham, Rance, and Blake (2010), people with FM have to struggle to gain recognition of their condition and to be taken seriously.

The majority of people with FM are women between the ages of 20 and 50 (Reiffenberg & Amundson, 1996). Fibromyalgia has an unclear aetiology with the consequence that diagnosis is

based on criteria (Wolfe et al., 1990). Fatigue, poor quality sleep, headache, stiffness, and perceived weakness are common symptoms among people with FM (Bennett, 1995; Bennett, Jones, Turk, Russell, & Matallana, 2007; Mease, 2005; Merskey & Bogduk, 1994). The unclear aetiology of FM also means that no therapy is broadly effective (Solitar, 2010), instead treatment is mainly focused on palliation. Studies (Kengen Traska, Rutledge, Mouttapa, Weiss, & Aquino, 2010; Löfgren, Ekholm, & Öhman, 2006) have shown that women with FM found a variety of strategies for managing the variability of the symptoms and to gain control over the situation. According to Hallberg and Bergman (2011) women with FM used different strategies to minimize the imbalance between activity and recovery. However, the unpredictable character of the illness made the person with FM insecure and led to a lack of self-confidence (Lempp et al., 2009).

The right kind of support is crucial for being able to manage with FM (Cunningham & Gillings, 2006) and Sallinen, Kukkarainen, and Peltokallio (2011)

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have shown the importance of peer support for women with FM and their ability to cope. Other studies (Paiva & Jones, 2010; Peterson, 2007; van Wilgen, Bloten, & Oeseburg, 2007) have shown the multidisciplinary approach to treatment to be the most beneficial for people with FM. Hallberg and Bergman (2011) suggested health promoting courses based on the principles of cognitive behavioural therapy (CBT) as help for women with FM to learn strategies to divert attention from pain.

The majority of people with FM not only experience pain throughout most of their waking hours but live with pain almost constantly (Bennett et al., 2010; Henriksson, Gundmark, Bengtsson, & Ek, 1992). Schaefer (1997) reported that pain was the most common symptom experienced by women with FM and that there was a significant pattern in terms of the relationship between pain, sleep, and climatic conditions. According to Söderberg and Norberg (1995) women with FM described their pain using metaphors that suggest a torture-like experience. The pain was described as being constant and without any distinct bodily location. Research (Åsbring & Närvänen, 2002; Söderberg et al., 1999) has shown that living with an undiagnosed condition, such as FM, means living in uncertainty and not being seen as a credible person. Being met with disbelief and not being seen as credible harms a person's dignity and causes additional pain (Söderberg et al., 1999).

Pain for people with FM is a whole body experience (cf. Schaefer, 1997; Söderberg et al., 1999) and the inability to control and reduce pain impacts negatively on the person's experience of quality of life (Arnold et al., 2008; Burckhardt, Clark, O'Reilly, & Bennett, 1997). Even though pain is one of its hallmark symptoms, there is currently a lack of research about the meanings of pain for women with FM. Understanding meanings of pain for women with FM would increase the possibilities of facilitating support and guiding health care providers in their attempts to empower women with FM to manage life with the illness. Thus, the aim of this study was to elucidate meanings of pain for women with FM.

## Method

### *Participants and procedure*

A purposive sample of 15 women with FM participated in the study. The criteria for participation was that the women were diagnosed with FM in accordance with the ACR criteria (Wolfe et al., 1990). The women were aged between 38 and 64 years ( $md = 54$ ), had experienced symptoms for between 6 and 38 years ( $md = 25$ ), and the time range from diagnosis varied from 1 to 20 years ( $md = 10$ ). Nine women

were married, two were co-habiting, and four were single. All had children and five had minors still living at home. Eleven women had a vocational education, three had elementary schooling, and one had a university education. Four women were employed or looking for work, six were on sick leave, three received a state pension, and two a disability pension.

The participants were recruited from a rehabilitation centre ( $n = 4$ ) and from the Associations for Rheumatism and FM ( $n = 11$ ), all in the northern part of Sweden. The head of the rehabilitation centre and the Presidents of the Rheumatology and FM Associations were asked to pass on information about the study to their patients and members. They were asked whether they were interested in participating in the study and a total of 15 women agreed to do so. They were sent an information letter about the study, including a reply form containing written consent regarding participation. After receiving approval for further contact, the first author telephoned the women to obtain further information and to make appointments for the interviews.

### *Ethical considerations*

Before the interviews all participants were given information about the nature of the study, both written, by letter, and verbal. They were also informed that their participation was voluntary and that they could withdraw from the study at any time without giving any explanation. All participants gave their written consent, were guaranteed confidentiality, and a personalized presentation of the findings. The study was approved by the Regional Ethics Review Board (Dnr. 09-066Ö).

### *Interviews*

Personal interviews using a narrative approach were carried out with the participants. The purpose of the narrative interview is to create a condition for understanding the meanings that emerge during the dialogue (Mishler, 1986). The women were asked to talk as freely as possible about their lived experience of pain. Clarifying questions were asked when needed, e.g., "What did you feel?" and "Can you give an example?" The interviews lasted between 45 and 115 min ( $md = 76$ ) and took place in accordance with the women's wishes either at their homes ( $n = 13$ ) or in a quiet room in an office at the association ( $n = 2$ ). The interviews were recorded and later transcribed verbatim by the first author.

### *The phenomenological hermeneutic interpretation*

As the aim of the study was to elucidate the meanings of pain for women with FM, we chose to

analyse the interview texts using a phenomenological hermeneutic method of interpretation described by Lindseth and Norberg (2004) and inspired by the philosophy of Ricoeur (1976).

The phenomenological hermeneutic interpretation consists of three phases: the naïve understanding, the structural analysis, and the comprehensive understanding. In the naïve understanding the text was read several times in order to grasp its meaning as a whole. The naïve understanding guided the second phase—the structural analysis. In the structural analysis the text was divided into meaning units guided by the aim of the study. The meaning units were condensed and then sorted, based on similarities and differences, into sub-themes and themes. In order to achieve validation the sub-themes and themes were compared with the naïve understanding. The final phase, the comprehensive understanding, was developed from and supported by the naïve reading, the structural analysis, the researchers pre-understanding, and the literature. The text was then interpreted in its totality, which resulted in a new comprehensive understanding (cf. Lindseth & Norberg, 2004; Ricoeur, 1976). The literature for the interpretation was chosen with the aim of revising, widening, and deepening our understanding of the text. The perspective in the chosen literature was not forced on the interview text; instead the aim was that the literature would illuminate the interview text and the interview text would illuminate the literature (cf. Lindseth & Norberg, 2004). The interpretation was conducted in as open-minded a manner as possible, with an awareness of our pre-understandings as nurses and as nurse researchers.

## Findings

### *Naïve understanding*

Pain was something that invaded the whole body for women with FM. It was always present, unpredictable, and fluctuating. Pain dominated daily life and as it was invisible to others, women with FM experienced feelings of being met with disbelief and not being taken seriously by others. The women seemed to experience body and mind as one incoherent painful whole that was an obstacle in their daily life. Pain for women with FM could be described as differing; they experienced both an everyday pain that was easier to manage and a contrasting more severe pain that they described as being overwhelming and almost unbearable. For a long time the women had hoped for recovery but had reconciled themselves to the fact that pain was a part of their everyday life and had learned to live with it.

### *Structural analysis*

The structural analysis resulted in two themes with five sub-themes. The two themes are “Experiencing an unwilling body” and “Experiencing a good life despite all.”

#### *Experiencing an unwilling body*

The theme “Experiencing an unwilling body” consisted of the three sub-themes: living with an invisible change in the body, feelings of being constrained by an unfamiliar body, and trying to endure an overwhelming feeling of unpredictability.

*Living with an invisible change in the body.* The women with FM described how their body was in pain the whole time, but as it was an invisible bodily feeling they felt questioned. They said that they were not listened to or taken seriously regarding their invisible pain. As they did housekeeping and shopping despite their pain, the women with FM felt their credibility was questioned. This led to feelings of sadness, anger, and frustration. As one woman said, “Others can’t understand what they can’t see.” Women with FM described how they had repeatedly been disbelieved by health care personnel. Not even their family understood their experience of pain.

You aren’t believed, so you feel all the time that you have to explain. Explain what you have done and what you are suffering from and you have to say; now I’ve been in bed for 3 days because I’ve done that and that. Maybe you have seen me changing curtains or something.

The women with FM said that other people’s judgemental attitudes were one reason they did not ask for help. Fear of being seen as silly, lazy, and stupid made them reluctant to share their experiences and sometimes even made them doubt their own feelings.

No, I prefer not to say so much, I was mocked at work when I had a hard day and had a lot of pain under my feet. It’s like walking on glass actually and I had taken with me a paper about the pain so I could explain and then she came [the boss] and saw the paper and mocked me about it and that’s why I’ve backed off and I don’t want to tell anyone about the pain.

*Feelings of being constrained by an unfamiliar body.* Women with FM described how their bodies no longer functioned as they did when they were healthy. The changed bodily function was related

to the fluctuating, ever-present pain. The women had to consider carefully doing such daily chores as cooking, walking, and writing. They planned and wanted to do things but described how they had to wait for their body to catch up with their ideas. One woman said:

When I'm in pain my body doesn't want to function as normal. In some way I don't know how to explain it either, it's like the brain disconnects that I have a cup in my hand and when I want to do something else it's like it stops functioning.

The women with FM described, in addition to pain, other physical sensations such as tender skin, swelling, numbness, and sensitivity to cold. This induced feelings that their body was broken and that affected their mood. It was frustrating to live with a body that had become unknown to them. Times of increased pain were experienced as leading to new bodily phenomena (i.e., lack of concentration, sensitivity to noise, and memory loss) that further limited everyday life. Women with FM described pain as paralysing and as if it had a life of its own. These times were hard to cope with and induced feelings of sadness and thoughts about whether life was worth living.

You have pain all over your body, it's like the head wants to get up but the body wants to lie down. It's like a total pain in my whole body and my head feels heavy. There is nothing to do but lie down.

*Trying to endure an overwhelming feeling of unpredictability.* Women with FM described how they felt overwhelmed by a constant, unpredictable, and unbearable pain all over their body. They were never totally pain free as pain was always present, but sometimes they experienced a more intense pain. These different pains could be described as an everyday pain and pain on pain. This was experienced as being different dimensions of pain and was hard to explain. The unbearable, unpredictable, and overwhelming pain affected everything in the women's lives. Usually the pain became overwhelming after they had done some heavy housekeeping jobs such as vacuuming or window cleaning. Now and then, however, pain just came without any forewarning, which made it hard for women with FM to plan ahead. Women with FM said that it was important to learn to know their bodies and what they were able to do. "Of course it [the pain] affects you because you can't manage. You know, there is a limit to how much pain you can manage. It feels hard."

Women with FM described feelings of never being totally rested because of the constant pain. It was difficult to get comfortable at night when one side of the body was awakened by pain and the other side had to move to counter the stiffness. Active days led to worse nights and women with FM said that they tried to endure the nights and find relief through painkillers or sleeping pills. After a sleepless night because of the pain, the next day brought feelings of morning stiffness and total exhaustion, which made it hard to get started and forced the women to rest during the day. Women experienced their fatigue as being intertwined with the pain and when the pain became worse they felt empty, weak, and powerless.

My body is stiff and then I get pain, like a hard pain in my back and then I'm tired, tired, tired all the time and it feels like I can't open my eyes properly for the whole day.

#### *Experiencing a good life despite all*

The theme "Experiencing a good life despite all" comprised two sub-themes: finding relief through distraction and feelings of reconciliation.

*Finding relief through distraction.* The women with FM said that walking outdoors, gardening, and doing handiwork enabled them to overcome their experience of pain and distracted their thoughts. The women described these distractions as worthwhile, even if the pain increased subsequently, as they were ways of normalising everyday life.

I like to arrange the flower-bed and ... I can get it [pain] really bad, then I take it more calmly and sit down for a while and if it feels better I continue. I can't just lie down you know because then life ends completely.

The women described how they diverted the pain by helping the children/grandchildren and others. When with the children/grandchildren, the women could totally concentrate on a task. They found meaning in helping others who were in a worse situation than themselves. Being with friends was described as fun and enabled them to focus on things other than pain. This was important for their self-esteem and gave them the strength to keep control, struggle, and never give up.

I keep on going quite a lot ... and I think this is mostly because I have to distract myself from the pain in some way. ... If I do something else and think of something else then I don't think on, well

when something is fun, then you forget [the pain] for a while.

The women with FM said that sometimes everything was about thinking positively in order to endure the situation. One woman said: “The only way to survive is actually to be optimistic and try to make the best of everything.” Through adapting to everyday life and finding new ways of being, they learned to maintain a balance between activities and pain. The women wanted to be like everybody else and occasionally the invisibility of the pain and illness made this possible.

But no one knows what I have because I don't use crutches and don't have any rashes. I can't stand in the yard and preach about myself so being able to go out and be a normal mother is really good.

*Feelings of reconciliation.* Women with FM said that they did not accept the pain but had learned to live with it. It had taken them a long time to learn to accept that life would be like this. They had also learned to care for and comfort themselves. Regardless of their difficulties the women with FM said that they were living a good life. They explained that it was not desirable to live with pain but it could be constructive because they had learned to live a calmer life, as one woman expressed it: “to be a better human being.”

It's like I say you can't do anything but put up with it, I have had it for such a long time so I will probably have to live with it [the pain]. It has to be like this and I usually say that there are others who are worse off.

Regardless of being limited by pain, women with FM felt free to do what they wanted. Retaining old interests but pursuing them under new conditions, participating in associations, and continuing to work despite a reduction in working hours was ways of retaining a life outside the home. For a long time, the women had nourished a hope for recovery and wanted life to be as it was before but they had come to understand that the pain was a part of their everyday life and had become reconciled to it.

### **Comprehensive understanding and reflections**

The aim of this study was to elucidate the meanings of pain for women with FM. The study shows that, for the women, pain means living with an unpredictable pain that dominates their daily life and simultaneously feeling that they are doubted because of the invisible nature of the pain. Despite this, all the women tried

to normalize life by doing daily chores as a way of alleviating the pain.

The women with FM described experiences of not being believed or taken seriously as their pain was invisible to others. According to Kleinman (1988), all those who suffer chronic pain share one common experience—their credibility regarding their experience of pain is questioned by others. The person who is not taken seriously, listened to, or seen by others develops a feeling of insignificance. This feeling of being insignificant implies powerlessness and violates their sense of dignity and credibility (Eriksson, 1994). Not being seen as a credible, significant person can induce a feeling of not being confirmed (cf. Gustafsson, 1992; Söderberg et al., 1999; Söderberg & Lundman, 2001). Confirmation is important in relationships between people. To be confirmed is to be acknowledged, to be allowed to be as one is (cf. Söderberg et al., 1999). Buber (1997) states that people wish to be confirmed as what they are and what they can become; in contrast, lack of confirmation can cause suffering. According to Cassell (2004), the meaning of suffering is to be seen as a kind of alienation and a threat to a person's integrity. For women with FM this implies a double burden; they live with an aggressive, unpredictable pain and are questioned by others because of the invisibility of that pain. This is in line with Scarry (1985, p. 4) who noted that “to have pain is certainty, to hear about pain is to have doubt.” This means that when women with FM are doubted by others concerning their pain experiences it adds to their suffering (cf. Lawler, 1997).

Women with FM said that their bodies felt changed compared to when they were healthy. Their bodies were full of unfamiliar sensations and the ability to live as they did before felt altered. For a person in pain, pain is not something detached, it occupies every fibre of one's body and is inseparable from the self (Madjar, 2001). According to Toombs (1993), when someone is healthy they take their body for granted, but when someone falls ill this no longer applies. This is based on the reasoning of Merleau-Ponty (1996), who argued that human beings have access to the world through their body and when their body changes their perception of their surroundings also changes. For women with FM, common everyday tasks were demanding and required reflection to allow body and mind to cohere. This can be understood in terms of the writings of Frank (2002) who believed that a healthy body coheres with its environment, in contrast to the sick body that is disconnected from what surrounds it. The natural bodily rhythm is lost for a person in pain and, according to Toombs (1993), this means an awareness of bodily disruption.

Women with FM described being overwhelmed by a pain that was constantly present. According to Sartre (2003), the lived experience of pain implies a painful experience of life. The women with FM described the constantly present pain as a manageable everyday pain; however, they also described experiencing a kind of duplicated pain, which felt unbearable and made them feel that their daily life was controlled by pain. This can be understood in terms of Sartre's (2003) argument that for the person in pain, pain can never be an object simply located in the body. Instead, pain manifests itself as an inability to concentrate and pursue common daily tasks. The immediate subjective experience of pain is not one of a pain somewhere in the body; instead, the body in itself is pain. In this study, women with FM said that it was difficult to plan ahead. According to Toombs (1993), for the person who is in pain, the body is experienced as an object that demands all their attention. Comprehending the body as a painful object implies that the person is bound to suffer whatever the body suffers (Toombs, 1993).

For women with FM, daily life was strongly influenced by the unpredictability of the pain, as it impacted on their chance of finding relief and taking control over their everyday life. This can be understood from the research of Mishel (1988) and Neville (2003) who emphasised that the unpredictability in illness can be experienced as a threat by the person who is ill. According to Toombs (1993), the experience of uncertainty in illness means a loss of wholeness, which implies a loss of control when the familiar everyday life becomes unfamiliar. For the person who is ill, this can be understood as the uncertainty of living with considerable anxiety and fear. Living with the threat of unpredictability accompanied by anxiety and fear can strongly influence the sick person's possibility of managing daily life. They can also feel that it is difficult to communicate their experience to others (Neville, 2003; Toombs, 1993). Women with FM said that the pain was intertwined with their experience of fatigue. Intertwined bodily sensations were described in the research by Söderberg, Lundman, and Norberg (2002) who showed that pain causes fatigue and, in turn, fatigue strengthens pain. Similarly Olsson, Lexell, and Söderberg (2005) showed that women with multiple sclerosis (MS) were strongly affected by intertwining bodily sensations in everyday life.

The women with FM described how they could distract their minds from the pain by focusing on daily chores. This change of focus was seen by the women as a way of finding relief. They described being completely concentrated on and caught up in the essentials of everyday life, as being worthwhile despite it resulting in increased pain. According to

Dewar and Morse (1995), the person in chronic pain learns to bear the pain and develops strategies to minimize or distract attention from it once the situation becomes part of their existence. The women with FM said they found meaning in helping others who were worse off than themselves. This can be understood from the writings of Frank (2004) who states that the wish to take responsibility for others means taking an active role in creating life in a desired way.

The women with FM said that they did not accept the pain but had learned to live with it. This is similar to the results of Olsson, Skär, and Söderberg (2010) who found that women with MS can feel well by learning to live with the fact that their everyday lives have been changed and by approaching life as it is. In this study, despite their difficulties, women with FM had come to terms with the limitations and felt they led a good life. In their research into well-being, Todres and Galvin (2010) describe people's openness towards seeing things as they really are and their ability to be at home with their situation, at peace with external circumstances. In this study, women with FM said that even if it had taken a long time for them to regard pain as a part of their everyday life they had eventually found new ways of living and maintaining a balance between activities and their experience of pain. Register (1989) argues that acceptance means taking responsibility for constructing a life in the spaces between moments of dysfunction and implementing habits that will keep these to a minimum intensity. Corbin and Strauss (1987) believe that by coming to terms with the illness the person can overcome their body in new ways, even if their performance is limited. In this study, there is an understanding that women with FM restored harmony and established a new and meaningful relation to their body and the world; their painful body became their habitual way of being-in-the-world. Despite all, the women said that they felt free to do whatever they wanted and that they were pursuing everyday life under new conditions. According to Merleau-Ponty (1996), human perception is embodied and when the body does not behave as expected the familiar way of pursuing daily life needs to be regained. The familiar way of being-in-the-world can be re-established if people can get used to and no longer feel unfamiliar with the changed conditions of everyday life.

### **Methodological considerations**

In this study women's narrations have been interpreted using phenomenological hermeneutics. The method of interpretation was chosen because of its relevance in elucidating the meanings of people's

experiences. During interviews, the women narrated their lived experiences freely. This pre-supposed that the women were aware of their lived experience, were willing to talk, and could find the words to narrate (cf. Lindseth & Norberg, 2004). In this study the women wanted to narrate their experiences. We argue that these are the very most significant experiences of living with pain, as they were experienced by the women at the time of the interview. To minimize the risk of misunderstandings during the interviews, we checked our pre-understandings by using probing questions in order not to make definite what is indefinite (cf. Dahlberg, Dahlberg, & Nyström, 2008). The interviews were rich, had depth, and revealed variations in the women's lived experiences (cf. Lindseth & Norberg, 2004).

The interpretation we present in this study is the one we found to be most likely. According to Ricoeur (1976), a text can always be interpreted in more than one way. We considered and compared possible interpretations (cf. Lindseth & Norberg, 2004) in critical discussions with peers (Ricoeur, 1976). According to Dahlberg et al. (2008) our pre-understanding cannot be eliminated, but it can be bridled so as not to have an uncontrollable effect on our understanding. When conducting this study, we consistently tried to keep our pre-understandings in check (cf. Dahlberg et al., 2008), through critical peer discussions concerning our evolving understanding of the phenomenon in view (cf. Ricoeur, 1976). The findings in this study represent one way of understanding meanings of pain for women with FM. The findings cannot be generalised but can be transferred to similar situations or participants (Lindseth & Norberg, 2004).

## Conclusions

This study shows that the meanings of pain for women with FM are living with a double burden: living with an aggressive, unpredictable pain and being doubted by others because of the invisibility of the pain. The ever-present pain was described as unbearable and overwhelming and dominated the women's whole life but despite this they described themselves as living a good life. In order to support the women in their ability to manage pain and feel well despite pain, it is important that nurses and health care personnel acknowledge and understand women with FM and their experiences of pain.

## Acknowledgements

We thank the women who volunteered to participate in the study and Pat Shrimpton for revising the English.

## Conflict of interest and funding

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article. The authors disclosed receipt of the following financial support for the research and authorship of this article: Department of Health Science, Luleå University of Technology, Luleå, Sweden.

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