Published in final edited form as:
Patient Educ Couns. 2008 October ; 73(1): 114–120. doi:10.1016/j.pec.2008.06.005.

Patient Perspectives on the Impact of Fibromyalgia

Lesley M. Arnold[1], **Leslie J. Crofford**[2], **Philip J. Mease**[3], **Somali Misra Burgess**[4], **Susan C. Palmer**[4], **Linda Abetz**[5], and **Susan A. Martin**[6]

1*University of Cincinnati, Cincinnati, OH*

2*University of Kentucky, Lexington, KY*

3*Seattle Rheumatology Associates, Seattle, WA*

4*Mapi Values, Boston, MA*

5*Mapi Values, Bollington, UK*

6*Pfizer Inc, Ann Arbor, MI*

Abstract

Objective—The objective of this study was to elicit and assess important symptom domains and the impact of fibromyalgia on patients' quality of life and functioning from a patient's perspective. The intention was to collect this information as part of an overall effort to overcome shortcomings of existing outcome measures in fibromyalgia.

Methods—This was a qualitative study in which six focus group sessions with **48 women** diagnosed with fibromyalgia were conducted to elicit concepts and ideas to assess the impact of fibromyalgia on their lives.

Results—The focus groups conducted with fibromyalgia patients identified symptom domains that had the greatest impact on their quality of life including pain, sleep disturbance, fatigue depression, anxiety, and cognitive impairment. Fibromyalgia had a substantial negative impact on social and occupational function. Patients reported disrupted relationships with family and friends, social isolation, reduced activities of daily living and leisure activities, avoidance of physical activity, and loss of career or inability to advance in careers or education.

Conclusion—The findings from the focus groups revealed that fibromyalgia has a substantial negative impact on patients' lives.

Practice Implications—A comprehensive assessment of the multiple symptoms domains associated with fibromyalgia and the impact of fibromyalgia on multidimensional aspects of function should be a routine part of the care of fibromyalgia patients.

Keywords

fibromyalgia; patient focus group; symptom domains; quality of life

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Corresponding author/reprint requests: Lesley M. Arnold, M.D., University of Cincinnati Medical Center, 222 Piedmont Avenue, Suite 8200, Cincinnati, Ohio 45219, Phone: 513-475-8110, Fax: 513-475-8116, Email: Lesley.Arnold@uc.edu.

1. Introduction

Fibromyalgia is a chronic disorder characterized by persistent and widespread pain. It is common in the United States with an estimated prevalence of 2% in the adult general population. Fibromyalgia disproportionately affects women, with a prevalence of 3.4% in women, compared with 0.5% in men (1). Worldwide prevalence rates in adults range from 0.5-5% (2). Fibromyalgia is defined by the American College of Rheumatology (ACR) as chronic (≤ 3 months) mon widespread pain and pain on palpation of at least 11 of 18 tender point sites throughout the body (3). Recent evidence suggests that there is a dysregulation of pain pathways leading to central pain augmentation in patients with fibromyalgia (4).

In addition to pain and tenderness, patients with fibromyalgia also report other symptoms, including sleep disruption, fatigue, depression, anxiety, memory and concentration problems, headaches, numbness/tingling, and others (3). These multiple symptoms may have an immense impact on daily life, limiting participants' functioning and emotional well-being (5,6).

Fibromyalgia is diagnosed through a combination of patient history and physical examination. While not required, exclusion of other causes for symptoms attributed to fibromyalgia is important clinically for optimal management (7). Fibromyalgia frequently co-occurs with other medical conditions, and it is important to recognize and treat fibromyalgia as a distinct disorder. Some clinicians may not recognize fibromyalgia or may view the condition as a psychiatric disorder or as simply not credible. As a result, patients can be left feeling confused and frustrated and are often left to cope with symptoms and the related impact on their own (5,8). However, this is changing as clinicians become more aware of the condition and treatment options increase.

Previous qualitative studies of patients with fibromyalgia have used individual patient interviews to explore the personal experience of living with fibromyalgia. (9-16). In these studies, patients consistently described symptom domains that interfered with their function and quality of life, including pain, fatigue, sleep disturbance, cognitive difficulties, and mood disturbances such as depression. Common themes about the impact of fibromyalgia also emerged from these studies. Patients reported difficulty dealing with a disorder that has no outward signs, leading to concern about not being taken seriously by their physicians or others. The unpredictable and fluctuating course of the symptoms interfered with the patients' ability to plan work or social activities. Patients had to change their self perception and the way they conducted their lives to accommodate fibromyalgia. Activities often took more effort and time to complete, and patients had to pace themselves and prioritize activities to conserve their limited energy. Patients commonly experienced loss of intimacy with partners and social isolation. Several factors were identified that affected the course of their symptoms, including weather, being sedentary or overactive, and stress.

Clinical trials of the treatment of fibromyalgia have incorporated some of the symptom domains and impacts described by patients in these previous qualitative studies. However, there is still lack of consensus about the full set of domains that should be evaluated in treatment trials of fibromyalgia or as part of routine assessment in clinical settings. The underlying patient research to identify the entire set of domains important to patients with fibromyalgia through spontaneous focus group elicitation has not been conducted. The goal of the present study was to conduct focus groups of patients with fibromyalgia to identify the key symptom and functional domains associated with fibromyalgia from the patients' view and to elicit their perspectives on the impact of fibromyalgia. The intention was to collect this information as part of an overall effort to overcome shortcomings of existing outcome measures in fibromyalgia.

2. Patients and Methods

2.1 Overview

A total of six focus groups were conducted (two focus groups at each of three sites) at the following sites: 1) Seattle Rheumatology Associates **(community-based rheumatology private practice)**, Seattle, Washington, 2) University of Cincinnati Medical Center **(university-based primary care private practice)**, Cincinnati, Ohio and 3) University of Michigan Medical Center **(university-based rheumatology practice)**, Ann Arbor, Michigan. The patients were identified by the investigators (LMA, LJC, PJM) from their outpatient clinics at each of these sites. The focus groups were conducted between August and September 2004. The Institutional **(Ethical)** Review Boards at each of the 3 sites approved the protocol, and all patients provided written informed consent after the study was explained and their questions were answered and before study procedures were initiated.

2.2 Entry Criteria

Female or male patients were eligible for the study if they were ≥ 18 years met the ACR criteria for fibromyalgia (3). Patients were required to speak English as the primary language and be willing and able to participate in a 2-hour discussion on the impact of fibromyalgia. Exclusion criteria were the presence of a life-threatening condition such as AIDS or cancer, an uncontrolled psychiatric disorder, or difficulty hearing.

2.3 Study Design

All patients were identified and evaluated by the investigators (LMA, LJC, PJM) at each of the sites, and fibromyalgia was confirmed using the ACR criteria. Demographic and medical history were also collected by the investigators. Patients and investigators were also asked to rate in a single question the overall fibromyalgia severity experienced by the patient (very mild, mild, moderate, severe or very severe).

Patients who completed the evaluation and met entry criteria were referred to the focus group moderator who scheduled the groups. Whenever possible, participants were placed into focus groups based on clinician-assessed severity. Such groupings were important to try to prevent participants with more severe fibromyalgia from dominating a conversation in which most of the other participants' experiences were not as severe.

All of the focus groups were conducted by the same experienced moderator (a male qualitative researcher with over fifteen years of experience in conducting focus groups (average of 80 sessions per year), but with no prior experience of fibromyalgia (so as not to lead the patients)). The duration of each focus group discussion was approximately two and one-half hours and all discussions were audiorecorded. The moderator led the discussions with a semi-structured guide, using open-ended questions, that covered topics related to general and treatment-related fibromyalgia experiences, and used projective techniques (such as envisioning fibromyalgia as an animal and stating the reason why that particular animal was chosen).

2.4 Analysis of Focus Groups

All focus groups were audio-recorded (with prior consent from participants) and transcribed verbatim. We used principles of grounded theory based on Strauss and Corbin's techniques and procedures (17). This is an inductive rather than a deductive approach to yield concepts and sub-concepts that may help develop a conceptual framework for assessing the impact of fibromyalgia on patients. The first four transcripts were coded by two experienced Mapi Values' qualitative researchers (Polyxane Mertzanis, MPH and Catherine Chen), with coding being driven solely by the data and not by pre-existing hypotheses. Coding was done 'by hand' using highlighter pens and notations, then quotes were entered by code into an excel spreadsheet. Of note, a single sentence within a transcript could include more than one code. For example: ‘I feel so depressed because of the constant pain’ would have been coded initially for ‘depression’; ‘pain’ and ‘pain frequency’. The coded transcripts were then checked by the Mapi Values’ project leader (Linda Abetz) (who has over 10 years of qualitative health psychology research experience) to ensure that the coding did not omit important information and to resolve any possible disagreements in coding. At this point, although a coding book was developed to aid consistency, at any time throughout the qualitative analysis, additional codes could be added. Finally, all of the coded transcripts were carefully reviewed by the coders and the project leader to observe patterns in the impact experienced by the participants (18). Nevertheless, even if only ONE patient mentioned a particular type of impact or symptom, that information was still reported, as well as examined for potential reasons as to why only one patient may have mentioned something (for example, a particular demographic). At this stage, broader codes may have been added (such as ‘mental health’ to include sub-domains of ‘depression,’ sadness, anxiety, etc). Participant quotes grouped by concept and sub-concept were then reviewed to determine the impact fibromyalgia had on patients’ lives.

3. Results

3.1 Patient Demographics

In total, 48 female subjects participated in the six focus groups. Eight patients participated in the first Seattle, WA focus group, and 10 participated in the second focus group. Seven patients participated in each of the first Cincinnati, OH and Ann Arbor, MI focus groups, and 8 patients participated in each of the second focus groups at each of these locations.

The majority (94%) of participants were white (n=45), and the average age was 51 years (range: 31-72 years). Detailed participant demographics are provided in Table 1. On average, participants were diagnosed with fibromyalgia approximately eight years prior to recruitment and participation in this study (range: 1-18 years). Most patients and clinicians rated the overall severity of the fibromyalgia as moderate (Table 2). The most common clinician-reported comorbid disorders were irritable bowel syndrome (N=28 [58%]), chronic fatigue syndrome (N=24 [50%]), migraine (N=24 [50%]), depression (N=21 [44%]), and anxiety (N=18 [38%]). Commonly used **medications** for fibromyalgia, **as** reported by the clinicians, were non-steroidal anti-inflammatory drugs, selective serotonin reuptake inhibitors, selective serotonin and norepinephrine reuptake inhibitors, gabapentin, zolpidem, opioids, and tricyclic antidepressants. However, during the focus groups, patients also mentioned additional ‘alternative’ therapies including: acupuncture, biofeedback, cranial sacral therapy, diet/exercise modifications, heat, hydrotherapy, massage, relaxation therapy, tai chi, use of transcutaneous electrical neural stimulation (TENS), and meditation/yoga.

3.2 Focus Group Findings

Overall the patients reported that the road to the diagnosis of fibromyalgia was frequently long and stressful. Several were initially misdiagnosed while others had to take charge of their own diagnosis and education. The majority of patients felt some relief at finally having a diagnosis. However, the lack of public awareness of fibromyalgia made it difficult for the patients to receive adequate support at times.

The impact of fibromyalgia on daily life was found to be substantial and similar across all of the focus groups. Table 3 lists the domains most frequently identified as having the greatest impact on the patients’ lives. The following summarizes the patients’ discussion of these key domains.

3.2.1.Pain—Participants expressed living with constant pain and described their inability to pinpoint the exact source or location of their pain (‘You are in enough pain that you have to hang onto the wall in order to stand up’). Participants most commonly characterized their pain as “achiness,” and “hurt all over,” with some also characterising the initial sensations as ‘skin sensitivity’ linked to a ‘burning’ sensation (‘like a really bad sunburn.’) They noted that long bouts of engaging in one activity could significantly worsen pain in the days after they had overextended themselves. Patients reported that exercise often made the pain much worse. Patients evaluated their days in terms of having a 1-hour, 2- to 3-hour, or a 4- to 6-hour window in which their fibromyalgia pain was not as intense and they could accomplish the day’s tasks. The window of less pain typically occurred from 10 o’clock in the morning to 3 o’clock in the afternoon. Participants rarely reported having two or three days in sequence in which they did not experience symptoms.

A few participants remarked that their muscles were constantly tense. Participants alternately described feeling as if their muscles were “lead jelly” or “lead Jell-O,” and this resulted in a general inability to move with ease and a feeling of stiffness.

3.2.2. Fatigue—Participants stated that fatigue (or lack of energy) was one of the worst symptoms associated with fibromyalgia. Fatigue, like pain, was a constant presence in the lives of participants, who often had to pace themselves to ensure that the tasks set for the day could be accomplished. They frequently cited the need to take naps and mentioned their tendency to fall asleep during the day or while performing tasks. Similar to pain, fatigue could be worse in the evening, but this was dependent on individual experiences. Because conserving energy was so important, some everyday tasks were ignored in favor of the larger, more important tasks; therefore, participants often neglected their household chores (‘It’s everything I can do to clean my body, to clean my clothes and to put food on the table. It takes all the energy I have in the world to do those things on a daily basis’). Their energy occurred in spurts throughout the day, and as with their pain experiences, where some participants were very aware of their windows of lesser pain, participants had to conserve precious windows of energy. As one patient put it, “...you get 10 gallons of gas a day and you use them up in a certain way....when you are done, all of a sudden there you are standing at the kitchen sink and you just can’t stand there another second. You can’t cook anymore, you can’t wash another dish. You just have to sit down. I can’t even talk.”

3.2.3. Sleep—Participants greatly desired an improvement in their ability to sleep, and many reported that pain interfered with sleep. Most participants indicated that both fatigue and pain were directly related to the quality of their sleep **(‘If I can get sleep, I can fix all the rest.’)**. Many participants experienced a great deal of difficulty in rising and beginning preparations for the day; this difficulty was often attributed to pain upon awakening.

Mornings were particularly difficult for participants because they had difficulty sleeping at night and woke up in pain. Many participants seemed to experience the most difficulty in rousing themselves, even those who described themselves as being a “morning person” before fibromyalgia onset (‘Well, I cannot sleep at all if I don’t have [medication], so...there is no sleeping without it ... And getting up in the morning was just brutal. It’s brutal. I have to drag my sorry butt out of bed every morning and go to work, and it’s hard’).

3.2.4. Cognitive Impairment—Fibromyalgia affected participants’ cognition, particularly their memory and thought processes. Participants reported not being able to operate at the same levels of mental acuity than they had prior to onset. Participants frequently forgot important tasks and were often unable to articulate their thoughts to others because fibromyalgia affected their ability to focus and express themselves clearly, which was often referred to as “fibro fog.” (‘Yeah, normal ordinary words that you’re trying to say just don’t come to you. I can relate to what she is saying. They just leave you. You can't say what you want to say'). They described feeling more disorganized and had difficulty with planning. Participants also lost the ability to respond quickly when asked a question or when asked to perform a task, particularly in work settings. During the focus groups, participants would frequently drop or struggle to remember words or lost track of what they wanted to say; they would then point this out to the moderator as an example of 'fibro fog.'

Some participants also stated that fibromyalgia had adversely impacted their ability to drive. In addition to the physical difficulties presented by driving for participants, fibromyalgia impacted participants' abilities to drive because they would often forget where they were going and had trouble focusing on the task of driving ('I'd been driving and going some place where I know very well where to go and all of a sudden, I know where I am, but I can't figure out how to get to where I want to go'). Participants found it difficult to become motivated to begin tasks because the constant presence of pain disrupted patients' concentration and depleted them of energy.

3.2.5. Emotional impact—Emotional disturbances most commonly experienced by fibromyalgia participants included depression and anxiety. Some participants reported that acute anxiety, panic, or depression were disruptive to activities that they were trying to complete ('...very depressed, would not get up out of a chair, pain constantly. I just didn't have anything to live for').

Patients also expressed feelings of embarrassment, frustration, guilt, isolation, and shame. Participants also mentioned that the embarrassment was often associated with lack of social acceptance of fibromyalgia or when it became apparent that their cognitive abilities no longer enabled them to perform simple tasks. Participants expressed frustration with regard to their inability to be understood by the medical community and by those around them, as well as frustration with themselves over their loss of cognitive abilities or loss of sexual intimacy.

Participants mentioned feeling guilt or shame when rearranging priorities due to fibromyalgia, such as taking better care of themselves rather than putting other family members or friends first. Others discussed feelings of isolation as well as a feeling of being burdensome upon their partners and/or children.

Participants discussed the importance of keeping their feelings of stress under control as a way of preventing flares, but the social, physical, and mental impacts of fibromyalgia simultaneously caused and increased their levels of stress. Patients felt that fibromyalgia was more difficult to manage when experiencing a great deal of stress. The stress imposed on patients with fibromyalgia due to an often tough road to diagnosis, treatment issues, and intense symptoms lead to a burden on their mental health.

3.2.6. Functional and quality of life impact—Social Impact: Fibromyalgia affected participants' ability to establish and maintain emotional and physical contact with those around them. Many patients described that they were unable to plan events because they could not predict how they would feel. The unpredictability of fibromyalgia symptoms made it difficult to be a part of regular social activities. They reported being reluctant to commit to social activities and feared being judged by others as unreliable. Some faced scepticism from unsympathetic peers and coworkers, leading to some loss of friendships. Participants reported that they were unable to maintain friendships or make new friends because they were unable to participate in social activities due fibromyalgia ('That's been the most disheartening thing for me because you're unreliable, totally unreliable, that's how I feel, and that is actually how you present yourself, and you lose your friends. And I have a couple now, but there's people who will never understand this. I've had people say to me, 'Jeez, you don't look sick' or a family member say to me, ‘I think you like to be sick’). Participants reported not being able to care for their own children due to their fibromyalgia. Time spent with families was often reduced, and families frequently had to compensate for the participant’s absence by taking on more chores. Those who were mothers could not assist their children with homework or other school-related activities. Participants also mentioned not being able to go on family trips (‘And it’s definitely changed my life, my family’s life. And I had to learn to modify my lifestyle. And I also learned that, you know, I was, you know, the same thing, working full-time, you know, busy social life, everything else. Now I find that I am very much a home person. And the important people are my husband and my children. And as far as socializing, there is, you know, maybe a -- maybe a few people that we will get together with, but everybody else that we used to do, I said I can’t do it’).

One of the largest impacts of fibromyalgia as reported by participants was the burden placed on spouses and partners, who often had to take on a greater share in household chores, childcare, and other family responsibilities. Some participants mentioned that the most significant impact of fibromyalgia on their marital lives was that the constant pain and fatigue of fibromyalgia had greatly decreased their libido and desire for sexual intimacy (‘He feels bad because [he] says I never seem interested, which, you know what, and I hate myself because it’s not who I was, that is not who he married, but three years into it. And now it’s to the point where I almost -- I think I make myself sick when I go to bed praying to God that he won’t touch me. And I say, what is wrong with me?’).

Impact on work and other activities: Participants reported having to frequently change jobs or take a reduction in hours due to the inability to perform repetitive tasks, type on a computer, or the inability to focus due to impaired concentration. Approximately half of the focus group participants had stopped working for income altogether (‘Being at early mid-career and having it all end. There is a lot of loss there, and I think I really resonated with something you said really early on about getting to a certain point where there is a lot going on and we are in our competency and we are really doing something that’s fascinating to us that’s the right place for us, and then we are not able to continue doing it, and we haven’t peaked our career, there is no satisfaction in being able to wrap it up and quit’).

Participants expressed financial repercussions with the loss of their mental capacity to perform jobs well enough to keep them. Financial situations were made worse by mounting medical bills after loss of income and health insurance. Participants also found it difficult to repay loans taken to finance advanced education. A few participants described not being given disability benefits until they had passed a battery of tests and appeared in court.

In some cases, fibromyalgia prevented students from completing or pursuing higher education altogether due to the inability to sit through the full duration of classes, or being able to focus long enough during class or on a specific assignment (‘I didn’t go to college because ... I was always extremely tired, and never felt good.’ Or ‘I think I missed an entire core of (high) school my senior year’). Others spoke of going to great lengths to attend classes (‘It’s half a painkiller before class and the other half after class just to get through the class. But I made myself do it and I do feel better for doing and yet it could be that I’m done for the day after that or I can only do a few things’).

Participants reported that their physical and emotional ability to complete tasks of daily living was severely limited by fibromyalgia because of pain, lack of energy, fatigue, and depression. Participants felt the most incapable of performing activities of daily living such as household chores (e.g., grocery shopping, house cleaning) and self-care (e.g., bathing and showering). Some participants reported that they could no longer engage in highly athletic leisure activities such as camping, hiking, and bicycling. In addition, participants mentioned that the constant pain of fibromyalgia prevented them from pursuing hobbies they had previously enjoyed. Team sports were restricted due to the inability to commit to a team due to pain (‘I think it’s because when I was diagnosed ... I loved to play team sports, and I had to come to accept the fact that because I couldn’t commit to the team with recognizing my pain...’). Travel became limited because participants were unable to sit for extended periods of time and often had difficulties with changes in temperature or barometric pressure common during air travel. Participants related several of the difficulties experienced while driving with fibromyalgia. The primary difficulty seemed to be an inability to sit still for an extended period of time, which was painful.

The all-female group of participants noted that it was especially frustrating for “driven” women to be unable to operate at their previous capacity. Alternatively, fibromyalgia allowed the women to legitimize taking more time for themselves when they would otherwise have focused their energies on others. Indeed, some speculated that women’s roles as caregivers resulted in stress that contributed to the development of fibromyalgia. A few participants stated that the condition forced them to place their own needs before the needs of others. Loss of former identity was strongly linked with loss of job and the inability to pursue one’s long-term career interests. One patient stated, “I had to give up my identity as a ... I was well respected in the field and had published...With the loss of job, means loss of money.”

3.2.7. Other reported symptoms of fibromyalgia—Participants described experiencing “extreme sensitivity to almost everything - to light, to sound, to temperature,” as well as being extremely sensitive to odors and chemicals commonly found in perfumes, cosmetics, aftershave lotion, petroleum products, household cleaners, dryer sheets, and laundry detergents. Patients were also highly sensitive to variations in weather such as changes in barometric pressure and the onset of winter.

Participants reported experiencing unusual skin sensitivity that they described as “burning” or “a really bad sunburn.” In addition, a few participants noted that their skin had changed in pigmentation or texture.

Participants found that they were forced to modify their diet to adapt to fibromyalgia. There were no discernible patterns in diet changes due to fibromyalgia across the six focus groups, but some participants reported not being able to ingest monosodium glutamate, and others reported severe reactions to other foods that would cause their symptoms to flare such as tomatoes, potatoes, frozen dinners, and fast food.

Some participants discussed their perception that their immune systems were weakened due to fibromyalgia, leading to an increased susceptibility to infections. Conversely, participants also reported that another consequence of fibromyalgia was that they placed more of an emphasis on maintaining their health.

Participants reported experiencing headaches, dizziness, nausea, upset stomachs, and irritable bowel. Participants felt that dizziness prevented them from accomplishing daily tasks; and also experienced dizziness while driving as well as staggering at times or “tripping over nothing.” Participants reported that they experienced involuntary and repetitive movements, such as restless legs, associated with their fibromyalgia.

When asked to choose an animal that best described fibromyalgia to them, a wide variety of animals were chosen, but the reasons for choosing them seemed to follow some patterns. Fierce animals such as fire-breathing dragons, pirrahna’s, snakes, lions, bears or tigers were selected because fibromyalgia was seen as ‘ferocious,’ ‘brutal,’ or ‘deadly’ while slow moving animals such as elephants, turtles and sloths were chosen due to the impact of fibromyalgia on patients ability to think or act quickly.

4. Discussion and Conclusion

4.1. Discussion

This focus group study revealed that fibromyalgia has a profound impact on patients‘ lives. The symptoms of fibromyalgia most consistently reported by patients included pain, fatigue, sleep disturbance, depression, anxiety, and cognitive impairments. Fibromyalgia substantially impaired the quality of life and adversely affected social and occupational function. The focus groups identified several domains that could be targeted in treatment of fibromyalgia.

The results of this study are consistent with previous qualitative studies using individual interviews to assess the impact of fibromyalgia (9-16). Notably, the patients experienced a loss of their former identities. The constant presence of fibromyalgia symptoms changed the way they led their lives. The severity and unpredictability of the symptoms made it difficult to function at work, social, or leisure activities. The lack of understanding or general acceptance of fibromyalgia contributed to social withdrawal and isolation.

Clinical trials of fibromyalgia have varied in the assessment of pain and other domains. A meta-analysis of fibromyalgia clinical trials using tricyclic medications, the most frequently studied pharmacological agents for fibromyalgia, demonstrated some of the problems associated with the lack of consistency in study design and outcomes (19). Among the nine studies included in the analysis, seven outcomes that were most commonly used included the patients’ self-ratings of pain, stiffness, fatigue, and sleep; the patient and the physician global assessment of improvement; and tenderness as measured by tender points. However, none of the studies included all of these outcomes. Other important symptoms identified by the focus groups, such as depressive and anxiety symptoms, and cognition were not explored by most of the studies. Furthermore, pain is the primary outcome in most recent clinical trials of fibromyalgia (20). However, these clinical studies have evaluated the effect of treatment on pain intensity and have not consistently explored the duration or course of pain, characteristics that were reported to be important by the patients in the focus groups. In addition, fatigue was typically described by patients in the focus groups as a physical tiredness, with low energy, increased effort with physical tasks and with overcoming inactivity, but it was also depicted as decreased mental endurance and slowed thinking and well as aversion to effort and feeling overwhelmed. Fatigue has been inconsistently evaluated in clinical trials (20), but from the patients’ perspective, is an important multidimensional domain to address in treatment.

Functional outcomes have also received inconsistent attention in clinical trials of fibromyalgia. There is only one disease-specific outcome measure for fibromyalgia, the Fibromyalgia Impact Questionnaire (FIQ), which includes items for physical function (21). However, FIQ functional items are oriented toward high levels of disability, and do not allow for an assessment of the degree of effort required to complete the task, a feature of function that the patients in the focus group found important. Furthermore, the FIQ does not adequately assess the other functional domains mentioned by the patients including the impact on social and occupational functioning. The available measures do not adequately capture the impact of fibromyalgia on patients’ lives that was consistently expressed by patients in this study and in previous qualitative work (9-16). Improved functional and quality of life measures for fibromyalgia are clearly needed.

According to the ACR criteria, fibromyalgia is characterized by pain and reduced pressure pain threshold, but, as discussed above, patients commonly experience other symptoms that in some cases have more impact on patient function, such as fatigue. Therefore, the focus groups findings will not only help expand outcome measures in clinical trials, but also have the potential to define fibromyalgia in a way that has clinical relevance for patients and clinicians.

Due to the study population of 48 patients, it is important that domains only rarely mentioned during the focus groups not be discounted. Furthermore, the wide range of impact reported by patients with fibromyalgia meant that it would be very difficult to successfully integrate all of these domains in one questionnaire or even a battery of several questionnaires. In order to further evaluate which domains are of most importance to fibromyalgia patients, to better select or design appropriate measures, we determined that all domains discussed during the focus groups be assessed using a clinician and patient Delphi exercise, which is a ranking of the domains most affected by fibromyalgia and most important to patients and clinicians. The focus group findings are therefore a first step in a process to identify important symptom domains. The results of a clinician and patient Delphi **will be published separately.**

Several limitations of this study should be considered. First, although the study was open to women and men, only women enrolled in the study. Although the majority of people diagnosed with fibromyalgia are women, future studies should include men in order to assess any variance in symptoms experienced by men or any differences in the way that fibromyalgia impacts the lives of men. Second, patients were recruited by the investigators and were required to be able to participate in a focus group and therefore may not be representative of all patients with fibromyalgia. Finally, while the size of the groups allowed for an intensive discussion, confirmatory information with a larger population of patients is needed.

4.2. Conclusion

In summary, from the patients' perspective, fibromyalgia is more than a painful condition. It is associated with multiple symptom domains and has a substantially negative impact on function and quality of life.

4.3. Practice Implications

A comprehensive assessment of the multiple symptoms domains associated with fibromyalgia and the impact of fibromyalgia on multidimensional aspects of function should be a routine part of the care of fibromyalgia patients in the clinic and in trials of fibromyalgia treatment.

Acknowledgements

We would like to thank Allan Benedict (A&K Research, Inc., Dearborn, MI) who conducted the focus groups, Polyxane Mertzanis, MPH and **Catherine Chen** (Mapi Values, Boston, USA), and John Coombs (Pfizer, Inc, Ann Arbor, USA) for their assistance with this work. This study was funded by Pfizer Inc. and by NIH (NIAMS R01-AR-05-3207, Dr. Arnold, Principal Investigator). Somali Misra Burgess, PhD, Susan C. Palmer, and Linda Abetz, MA, are employees of Mapi Values, who were paid consultants to Pfizer in connection with the development of the manuscript.

This study was supported by Pfizer, Inc. and by the NIH (NIAMS R01-AR-05-3207, Dr. Arnold, Principal Investigator).

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Table 1

Patient demographic characteristics

	Seattle n=18	Cincinnati n=15	Ann Arbor n=15	Total n=48
Women, n (%)	18 (100)	15 (100)	15 (100)	48 (100)
Mean age ± SD	52 ± 5	49 ± 11	50 ± 13	51 ± 10
Race, n(%)				
White	16 (89)	14 (93)	15 (100)	45 (94)
African American	0 (0)	1 (7)	0 (0)	1 (2)
Asian	1 (6)	0 (0)	0 (0)	1 (2)
Other	1 (6)	0 (0)	0 (0)	1 (2)
Highest level of education, n (%)				
Some high school	0 (0)	2 (13)	0 (0)	2 (4)
High school diploma or GED	1 (6)	1 (7)	2 (13)	4 (8)
Some college	0 (0)	6 (40)	6 (40)	12 (25)
Certificate program	0 (0)	3 (20)	0 (0)	3 (6)
College or university degree (2- or 4-year)	7 (39)	3 (20)	0 (0)	10 (21)
Graduate degree	6 (33)	0 (0)	4 (27)	10 (21)
Other	4 (22)	0 (0)	3 (20)	7 (15)
Marital or relationship status, n (%)				
Single	3 (17)	1 (7)	2 (13)	6 (13)
Significant other	3 (17)	1 (7)	0 (0)	4 (8)
Married	10 (56)	7 (47)	11 (73)	28 (58)
Widowed	0 (0)	1 (7)	1 (7)	2 (4)
Divorced	2 (11)	4 (27)	1 (7)	7 (15)
Other	0 (0)	1 (7)	0 (0)	1 (2)
Work status,[*] n (%)				
Full- or part-time	4 (22)	10 (67)	5 (33)	19 (40)
Part-time due to FM	1 (6)	2 (13)	1 (7)	4 (8)
Not working due to FM	2 (11)	1 (7)	2 (13)	5 (10)
Applied/ receiving disability	4 (22)	1 (7)	3 (20)	8 (17)
Looking for work	1 (6)	0 (0)	0 (0)	1 (2)
Full-time homemaker	0 (0)	0 (0)	0 (0)	0 (0)
Retired	1 (6)	0 (0)	1 (7)	2 (4)
Other	5 (28)	1 (7)	3 (20)	9 (19)

[*] Data presented is not mutually exclusive; patients may have reported more than one work status. FM, fibromyalgia

Table 2

Patient clinical characteristics

	Seattle **n=18**	**Cincinnati** **n=15**	**Ann Arbor** **n=15**	**Total** **n=48**
Years since diagnosis[*], mean ± SD	8 ± 4	8 ± 5	9 ± 6	8 ± 5
Range	1-15	2-16	2-18	1-18
Self-rated current overall severity of FM, n (%)				
Very mild	1 (6)	0 (0)	0 (0)	1 (2)
Mild	1 (6)	1 (7)	1 (7)	3 (6)
Moderate	7 (39)	11 (73)	9 (60)	27 (56)
Severe	9 (50)	3 (20)	3 (20)	15 (31)
Very severe	0 (0)	0 (0)	1 (7)	1 (2)
Missing	0 (0)	0 (0)	1 (7)	1 (2)
Clinician-rated current overall severity of FM, n (%)				
Very mild	1 (6)	2 (13)	0 (0)	3 (6)
Mild	4 (22)	1 (7)	8 (53)	13 (27)
Moderate	5 (28)	11 (73)	5 (33)	21 (44)
Severe	8 (44)	1 (7)	2 (13)	11 (23)
Very severe	0 (0)	0 (0)	0 (0)	0 (0)
Missing	0 (0)	0 (0)	0 (0)	0 (0)

[*] One participant reported being diagnosed six months ago. FM, fibromyalgia

Table 3

Key fibromyalgia domains identified by patients with fibromyalgia[*]

Physical Domain
Pain
Fatigue
Disturbed Sleep
Emotional/Cognitive Domains
Depression, Anxiety
Cognitive impairment (decreased concentration, disorganization)
Memory problems
Social Domain
Disrupted family relationships
Social isolation
Disrupted relationships with friends
Work/Activity Domains
Reduced activities of daily living
Reduced leisure activities/avoidance of physical activity
Loss of career/inability to advance in career or education

[*] Not ranked by order of importance