

Experience of fibromyalgia

Qualitative study

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abstract

OBJECTIVE To explore illness experiences of patients diagnosed with fibromyalgia.

DESIGN Qualitative method of in-depth interviews.

SETTING Midsize city in Ontario

PARTICIPANTS Seven patients diagnosed with fibromyalgia.

METHOD Seven in-depth interviews were conducted to explore the illness experience of patients diagnosed with fibromyalgia. All interviews were audiotaped and transcribed verbatim. All interview transcriptions were read independently by the researchers, who then compared and combined their analysis. Final analysis involved examining all interviews collectively, thus permitting relationships between and among central themes to emerge. The analysis strategy used a phenomenologic approach and occurred concurrently rather than sequentially.

MAIN FINDINGS Themes that emerged from the interpretive analysis depict patients' journeys along a continuum from experiencing symptoms, through seeking a diagnosis, to coping with the illness. Experiencing symptoms was composed of four subcategories: pain, a precipitating event, associated symptoms, and modulating factors. Seeking a diagnosis entailed frustration and social isolation. Confirmation of diagnosis brought relief as well as anxiety about the future. After diagnosis, several steps led to creation of adaptive coping strategies, which were influenced by several factors.

CONCLUSION Findings suggest that the conventional medical model fails to address the complex experience of fibromyalgia. Adopting a patient-centred approach is important for helping patients cope with this disease.

résumé

OBJECTIF Examiner l'expérience de la maladie chez des patients souffrant d'une fibromyalgie diagnostiquée.

CONCEPTION Une méthode qualitative d'entrevues en profondeur.

CONTEXTE Une ville de taille moyenne en Ontario.

PARTICIPANTS Sept personnes chez qui une fibromyalgie a été diagnostiquée.

MÉTHODOLOGIE Sept entrevues en profondeur ont été réalisées pour examiner l'expérience de la maladie chez des patients souffrant d'une fibromyalgie diagnostiquée. Toutes les entrevues ont été enregistrées sur bande sonore et transcrites intégralement. Les transcriptions de toutes les entrevues ont été lues individuellement par les chercheurs, qui ont ensuite comparé et combiné leurs analyses. L'analyse finale comportait une étude collective des entrevues, permettant ainsi de faire ressortir les relations entre et parmi les thèmes centraux. La stratégie analytique se fondait sur une approche phénoménologique et s'est déroulée simultanément plutôt qu'en séquences.

PRINCIPAUX RÉSULTATS Les thèmes dégagés de l'analyse interprétative dépeignent l'évolution des patients dans un continuum passant de l'expérience des symptômes à la recherche d'un diagnostic puis à l'adaptation à la maladie. L'expérience des symptômes comportait quatre sous-catégories: la douleur, un événement déclencheur, des symptômes connexes et des facteurs de modulation. La recherche du diagnostic s'accompagnait de frustration et d'isolement social. La confirmation du diagnostic amenait un soulagement ainsi que de l'anxiété face à l'avenir. Après le diagnostic, plusieurs étapes menaient à la création de stratégies d'adaptation influencées par divers facteurs.

CONCLUSION Les constatations portent à croire que le modèle médical traditionnel ne permet pas de répondre à la complexité de l'expérience de la fibromyalgie. L'adoption d'une approche centrée sur le patient est importante pour aider les patients à faire face à cette maladie.

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Cet article a fait l'objet d'une évaluation externe.

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Fibromyalgia, also known in the past as fibrositis, is a clinical syndrome that has an estimated prevalence of between 2% and 4% in the general population.¹ Despite publication of the American College of Rheumatology's 1990 criteria for classification of fibromyalgia² and official recognition of fibromyalgia by the World Health Organization,³ fibromyalgia syndrome is still a misunderstood disorder.⁴

Patients present primarily with chronic, diffuse musculoskeletal aching and soreness with no discernible pathophysiologic abnormalities.⁵ Many studies attempting to uncover the underlying pathophysiology of fibromyalgia have been published over the last 25 years.⁵⁻⁷ Many hypotheses have been explored, but no clear etiology has yet been demonstrated.^{7,8} Studies dealing with the psychological aspects of the syndrome have been mostly quantitative.⁸⁻¹² They have had contradictory and equivocal results.^{8,13} Few qualitative studies have been conducted in this area, and yet findings reveal that patients' responses to fibromyalgia are highly emotional and often debilitating.¹⁴

Many family physicians find it difficult to understand fibromyalgia because it challenges the conventional medical model of disease and leaves them without an approach to managing the syndrome. We undertook this qualitative study to explore the illness experience unique to patients with fibromyalgia. By gaining a more global understanding of fibromyalgia, physicians might be able to respond to patients with this disease in a patient-centred manner.¹⁵ The primary objective was to obtain a more comprehensive understanding of patients' personal perspectives on living with this syndrome.

METHODS

The qualitative method of in-depth interviews was used to explore the illness experience of patients diagnosed with fibromyalgia. Potential participants were recruited through an invitation to the membership of the Ontario Fibrositis Association local chapter consisting of approximately 150 people.

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Participants were purposefully selected using maximum variation sampling techniques to ensure that they reflected a variety of characteristics including sex, marital status, level of education, socioeconomic status, and experience of fibromyalgia.^{16,17} Seven participants were interviewed; recruitment was terminated when saturation was achieved.¹⁶ All invited participants agreed to participate.

The interviews followed a semistructured schedule of open-ended questions exploring knowledge, experience, behaviour, opinions and values, and feelings in order to obtain a comprehensive picture of each participant's perspective.¹⁶ All interviews were conducted by the principal investigator. The interview was initiated by an open-ended question: "Could you tell me about your experience of having fibromyalgia?" Further open-ended questions sought clarification and additional information about participants' unique experiences. Interviews were terminated when the researcher had clarified with participants that there were no further issues to be addressed. All interviews were audiotaped and transcribed verbatim. Data collection and analysis was an iterative process that included immersion and crystallization.^{16,18,19}

The researchers immersed themselves in the data by independently listening to tapes and reading transcriptions and field notes, then comparing and combining their analyses. Patterns, categories, and themes emerging from each interview were highlighted and investigated by further data collection and analysis, interpretive reflection, and a literature review focused on discovering other meanings.^{16,18,19} Final analysis involved examining all interviews collectively, thus permitting relationships between and among central themes to emerge.

Several techniques promoting credibility and applicability of findings were used including audiotaping, verbatim transcription, and extensive field notes gathered during both data collection and analysis.²⁰ In addition, researchers attended to personal and professional biases that could influence their interpretation of the data through discussion and reflection.¹⁶ At conclusion of the analysis, representatives from the Association de la fibromyalgie du Québec and expert informants from psychology, family medicine, and rheumatology were asked to reflect on the coherence and relevance of the findings based on their experience. This study received ethics approval from The University of Western Ontario's Review Board for Health Sciences Research Involving Human Subjects.

RESEARCH

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FINDINGS

Participants were six women and one man ranging in age from 38 to 47 (mean age 41). All participants had been diagnosed with fibromyalgia, which had been confirmed by a rheumatologist using the American College of Rheumatology's criteria and definition.²

Average age at onset of symptoms was 28 years (range 16 to 43 years). However, two participants recalled important events that had exacerbated their symptoms dating back to childhood. On average, 8 years had transpired between onset of symptoms and final diagnosis of fibromyalgia. Participants had been attempting to cope with the illness (time since diagnosis) between 1 and 13 years (mean 5). Five participants were married or involved with a partner, and two were divorced. Five participants had children, ranging in age from 7 to 28 years. Three participants were working part time while the rest were receiving some form of financial assistance.

Continuum of experience

The fibromyalgia experience, as reported by participants, spanned a continuum ranging from experiencing symptoms, through seeking a diagnosis, to establishing coping strategies once the diagnosis was made. These three areas were the key themes that emerged from the interpretive analysis.

Experiencing symptoms. Experiencing symptoms was composed of four subcategories including pain, a precipitating event, associated symptoms, and modulating factors. For participants, the experience of fibromyalgia began with a variety of symptoms, the most important one being pain: "It was in the chest; then, it went down into the ribs, the stomach, the pelvic area; I just seemed to be inflamed throughout all my organs...."

Beyond location, pain was also perceived as chronic and severe: "The pain that you feel overwhelms you, and it exudes from every pore in your body. You're just in pain; you look like you're in pain; you talk like you're in pain; you act like you're in pain...."

Symptoms were often experienced as a result of a precipitating event that prompted participants to seek help: "I didn't realize I had it until after I had a car accident. I didn't feel well for a long long time,... and I would feel all this pain."

In addition, participants described specific symptoms associated with the diagnosis of fibromyalgia. For example, participants often reported sensations of swelling and numbness: "My hands swell all over;

they seem to get swollen.... After walking, my toes are gonna get numb, and there is nothing I can do about that."

Included in the multiple factors affecting participants' symptoms were the weather, being sedentary, or conversely, being overactive. All participants acknowledged that stress played a part in their illness experience, specifically in the exacerbation of symptoms: "I was probably at the most stressed time in my life.... And I wonder if that has anything to do with why I developed fibromyalgia...."

Seeking a diagnosis. Securing a diagnosis for their symptoms was a challenge for participants. They had often seen many consultants, and the result was frustration and disappointment.

I saw different doctors, and they really had no idea. They said there was absolutely nothing wrong; I was in perfect health; all the tests they did were perfectly normal. When somebody keeps telling you it is all in your head; it is a psychological thing,... it only makes your condition worse. It's the frustration of it all.

Lack of understanding and acknowledgment of their symptoms extended to participants' personal relationships: "You tell somebody you got fibromyalgia, and they don't see an illness; they don't see a cut or a bruise.... So, they will say: 'Oh yeah! Sure you do!'" As a consequence, participants tended to keep silent for fear of rejection, which resulted in social isolation. "I became very closed off socially, because I didn't want to explain to anyone how bad I was feeling,... even to people that I've known for a long, long time. I'm afraid to be judged and I'm afraid to be rejected."

Once diagnosed, participants experienced a sense of relief now that their struggle was acknowledged and their illness experience legitimized. This sense of relief was diminished, however, by their uncertainty about the future. As one recently diagnosed participant recalled:

I really didn't know how to feel because I didn't know too much about it and [doctors] didn't know a lot about it.... I guess my main question is what's going to happen down the road? Is it going to get worse? Is it going to stay like this? I don't ever want to be in a wheelchair or have a walker.... Is that going to happen?

With the diagnosis of fibromyalgia confirmed, participants substantially reduced the amount of energy previously expended in finding a cause for their poor health, devoting their time and emotional energy to searching for more effective coping strategies.

Coping strategies. The continuum between diagnosis and coping included several steps beginning with understanding the illness and adopting accommodating behaviour, to accepting the illness and thus allowing the creation of adaptive coping strategies. Recognizing the individual nature of developing new coping strategies was essential:

This illness is something that you have to find out what works for you in coping. [T]here is no magic medication, and there is no magic operation, and there is no doctor that's going to make you wonderfully better.... You are going to have to do what is necessary for you.

Gathering information about fibromyalgia was a crucial step in understanding the condition. Frequently, participants had to rely on their personal initiative to obtain the information they needed. "Nobody bothered to tell me anything about what it was.... I looked in the library, and there was practically nothing.... Finally, when I went to the Arthritis Society, I realized there was information available."

Learning extended beyond accumulation of facts about fibromyalgia to encompass integration of personal experiences: "You have to know your own limits; there is a lot of trial and error."

Understanding the illness resulted in adoption of accommodating behaviours, an intermediate step along the continuum. These accommodating behaviours were characterized by rigid routines or protocols participants felt obliged to follow: "I know that it's an absolute crucial thing to get a good night's sleep; to go to bed at the same time; eating on time,... so everything has to be regular. And the more regular it is, the better I feel."

Participants differed in their views on the role of work in managing their fibromyalgia. This variation influenced development of accommodating behaviours and their final acceptance of the illness. One participant articulated the relief she experienced after obtaining a long-term disability pension: "The pain that I was experiencing, because I was working, was just intolerable; I just couldn't live that way.... I feel very relieved that I'm not forced to do that any more, that I'm an OK person if I accept that it is a disability."

Another participant, however, stressed the important role that her career played in her well-being: "Not working... was just making matters worse. There is volunteer work, and that is fine, to a certain extent; but it doesn't pay my bills and it doesn't really give me the same satisfaction as my work—even part time."

Participants who had progressed from acknowledgment to acceptance of their condition presented more effective and balanced coping strategies.

[C]oping methods that are common with arthritis are the same that work with fibromyalgia: the proper exercise routine, be at the pool, [take walks, get] regular rest periods, modify whatever needs to be modified in your home to make it easier for you to cope. Don't try to clean your entire house in 1 day or do all the laundry and ironing in 1 day; pace yourself.

Yet, in their ongoing efforts to cope with fibromyalgia, participants experienced many conflicting emotions.

Because you're a grandmother, your children expect you to want to hold your granddaughter, to babysit.... They expect you to do all these things.... But your body says, "no, you can't...." It's hard for them to understand, and it's hard for you to accept.... I can't hold her,... and that hurts! I find myself, personally, I can accept the pain more than I can the mental anguish that goes with it.

Essential to accepting and successfully coping with fibromyalgia was participants' ability to express feelings of loss and subsequent grief over their prior capabilities. Of equal importance was participants' recognition and acceptance of their current limitations void of guilt or anger:

You are dealing with the old person and the new person. The old person is saying: "This is what I used to be, and look what is happening now...." The new person can't do this, can't do that.... So, it creates a contradiction between the old self and this new self, which looks very different and limited.

In addition to implementing the many coping strategies described by participants, establishing a support system was viewed as critical. For all participants the self-help group was important during the initial phase of their illness, offering emotional support and reinforcing legitimization. As time went on, however, some participants perceived the support group as no longer providing them with encouragement and motivation: "At first, I found some comfort in it. It was nice to know that there were other people out there. I thought 'Gee! I'm glad I'm not the only person.' But now, as I've dealt with it, to me, the group was very complaining. [I]t was starting to get to me."

Many participants viewed establishing a trusted relationship with a physician as supportive:

You need to see the same person on a regular basis; you know the doctor and the doctor knows you.... And it should be somebody you can talk back and forth to; you feel comfortable to talk to the doctor, the doctor feels comfortable.... It's the type of person [who] can listen to you.

DISCUSSION

The key finding of this study is patients' detailed description of their journey along a continuum from experiencing symptoms, through seeking a diagnosis, to coping with the fibromyalgia syndrome. Prior studies tended to provide a snapshot of patients' experience of fibromyalgia and focused on specific aspects of the syndrome. Our findings provide valuable insights regarding the course of the illness that can assist physicians in developing a management plan directed at patients' current position along the continuum.

Participants' description of constant and severe widespread pain has been mentioned in other studies.^{10,21-25} Yet patients' personal narratives of pain in our study emphasize the debilitating nature of their symptoms.

Similar to our findings, prior studies have suggested a link between a precipitating factor, such as a traumatic event or medical illness, and onset of symptoms.²⁶⁻³⁰ While findings from retrospective studies do not provide sufficient evidence to prove a linear cause-and-effect association, this remains the patients' perception. Thus, attending physicians might understand challenges faced by patients better after acquiring a comprehensive history.

Associated disorders, as described by study participants, are in accordance with the polymorphous nature of the syndrome described in the current literature,^{2,21,23,26,31-34} as well as the role of modulating factors, such as weather or activity level.^{2,21,26,32,33} This reflects patients' ongoing need to understand and make sense of their confusing and complex symptoms.

Studies addressing various aspects of the relationship between mental stress and fibromyalgia have contradictory results.^{2,35-39} Yet, as patients attempt to make sense of their symptoms, the role of stress is key. Thus, patients' inquiries about the effects of stress could provide an opportunity for family physicians to explore its meaning for patients and what intervention, if any, is appropriate.¹⁵ As patients move along the continuum, symptoms will persist and require ongoing exploration and explanation by family physicians.

Establishment of a diagnosis was often painful and intrusive for participants on both physical and emotional levels. Perhaps the multiple medical investigations described by study participants could have been averted by family physicians who were prepared to address the uncertainty of the diagnosis. Our findings and those of prior studies raise the question of physicians' contributions to the quest for diagnostic

Key points

- This qualitative study describes the trajectory of the illness experience of fibromyalgia patients.
- Patients had different experiences along a continuum from feeling symptoms to seeking a diagnosis to adapting and coping with the illness. Patients' reactions varied with each stage.
- Knowledge of this disease experience can help family physicians provide individualized care for a problem that is poorly managed by the traditional medical model.

Points de repère

- Cette étude qualitative décrit le cheminement dans l'expérience de la maladie chez des patients atteints de fibromyalgie.
- Les patients ont vécu des expériences différentes tout au long d'un continuum allant de l'expérience des symptômes à la recherche du diagnostic pour enfin s'adapter et faire face à la maladie. Les réactions des patients variaient à chaque stade.
- La compréhension de l'expérience de la maladie peut aider les médecins de famille à dispenser des soins individualisés pour un problème que le modèle médical traditionnel ne prend pas bien en charge.

certainty, not always an achievable goal in medicine.^{21,40} Family physicians' acknowledgment of the limitations of technology, as well as a greater awareness of patients' illness experience, could lead to early recognition of the characteristics of chronic pain, which would ultimately avoid costly, futile, and potentially harmful interventions.^{21,41}

Failure by either professionals or friends and family to recognize fibromyalgia as a bona fide disease culminated in participants' experiencing social isolation, a theme that has been studied in relation to many medical conditions.⁴²⁻⁴⁴ Family physicians can assist patients in both addressing and altering the experience of social isolation.

For all but one of the participants, the legitimization provided by the diagnosis served as a springboard to beginning to learn coping strategies. It is important for patients to be told the name of their disease.^{45,46} From the family practice perspective, naming the illness is often difficult, but perhaps essential for patients with fibromyalgia.

Participants described a fluctuating course as they began to integrate coping strategies. This included several steps beginning with understanding the illness

and adopting accommodating behaviours, to accepting the illness and thus allowing creation of adaptive coping strategies. This finding expands the conceptual model proposed by Snadden and Brown,⁴⁷ who described the illness experience of patients with asthma. Their model depicted a continuum ranging from diagnosis to final acceptance of the illness.

Bombardier et al also reported that adjusting to chronic illness depended more on patients' coping responses and attitudes than on the severity of the illness.⁴⁸ Thus, family physicians need to be prepared to respond to each phase of patients' experiences.

Participants were divided over the role played by work in their illness experience. This reinforces the importance of assessing each case individually and taking into consideration patients' personal contexts.¹⁵ Further, family physicians are often gatekeepers as well as advocates for patients accessing long-term disability benefits, and detailed knowledge of patients' life circumstances can only enhance these roles.

The positive effect of attending a self-help group in the initial phase of participants' experience is well documented.^{49,51} The negative environment of self-help groups described by some participants, however, is not described in the current literature. Knowledge and awareness of patients' shifting needs for support along the continuum can assist physicians addressing patients' current needs and expectations.¹⁵

Limitations and future study

The individual and intuitive nature of qualitative inquiry precludes any attempts at generalization. Even if fibromyalgia is approximately eight to nine times more frequent in female than in male patients, we considered it important to invite at least one man to participate in our study.⁵² Potential effects of sex remain unclear and require future study.

The study was designed to offer an initial exploration of the unique illness experience of fibromyalgia patients and to help develop an approach to management of this syndrome. This will also require further study.

conclusion

Our findings and the controversy surrounding this clinical syndrome suggest that the conventional medical model fails to address the complexity of the fibromyalgia experience. Consequently, we recommend improved education for all health professionals regarding the illness experience of patients with

fibromyalgia. The study also highlights the need for clinicians to adopt a patient-centred approach¹⁵ to help their patients cope with fibromyalgia. ♣

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