

Perspectives on Living With Fibromyalgia

Global Qualitative Nursing Research
Volume 3: 1–13
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sagepub.com/journalsPermissions.nav
DOI: 10.1177/2333393616658141
gqn.sagepub.com



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Abstract

Perceptions of people living with chronic illness change over time, contributing to health-related stress that necessitates coping skills. Paterson's shifting perspectives model provides an explanation of chronically ill people's variations in attention to their symptoms. In this qualitative study, 20 people with fibromyalgia living in a rural setting were interviewed in 2013 with the aim of gaining insight into their experiences and the meaning-making associated with their chronic condition. Analysis of the interview data categorized five recurrent, or common, themes: experiences of loss, feelings of fear and uncertainty, influence of stress, stigmatization of the disease, and coping through courage. Difficulties attendant to losses, distress, and stigma associated with this chronic condition led the participants to report poor health-related quality of life. The study findings can be useful across clinical settings to nurses and other health care providers in understanding those diagnosed with fibromyalgia and their care needs.

Keywords

pain, chronic, content analysis, fatigue / exhaustion, fibromyalgia, nursing, quality of life, research, qualitative, interviews, semistructured, stress / distress

Received December 15, 2015; revised June 1, 2016; accepted June 6, 2016

Chronic illness is generally viewed as somewhat of a phased process in which those affected follow a predictable course of the disease. The implication is that there is an end to the chronic illness, which can be reached if the person has had the disease for a sufficient duration to progress through its earlier stages. In contrast is the view that living with a not-so-well understood chronic illness is an ongoing and shifting process in which people's perceptions are ever-changing to make sense of their experiences.

The experience of chronic illness and its reality for patients and their families should be a primary concern in the design of care interventions (Donnelly, 1993). Earlier, Sontag (1978) brought insight to working with those who live with chronic illness, declaring that we are all living in the "kingdoms" of both the well and the sick, with wellness determined by what is understood about well-being compared with being chronically ill. Paterson's shifting perspectives model describes how people's thoughts about their chronic illness contain elements of both illness and wellness (Paterson, 2001). Their perspectives represent beliefs, perceptions, expectations, attitudes, and experiences about what it means to have a chronic illness in a particular context. These perspectives represent how people respond to their symptoms, others around them, and situations such as their employment and social activities. As their perspectives change, so does the degree to which their chronic

diseases affect their lives. Paterson emphasizes that shifting perspectives are not right or wrong; rather, these shifts reflect the individualization of people's experiences with chronic illness, likely revealing their situations and needs at the time.

Significance of Fibromyalgia as a Chronic Illness

The etiology and mechanistic underpinnings of fibromyalgia (FM) are unclear; however, research findings support the theory of dysregulation of the central nervous system as the source of altered pain processing (Bellato et al., 2012; Jensen et al., 2012). People living with this chronic condition were selected as the population for this study because it is recognized as one of the leading and most difficult chronic pain disorders to diagnose and treat, and there is no known cure (Bellato et al., 2012; Institute of Medicine, 2012). Arriving at a diagnosis of FM might take more than 2 years, with patients seeing an average of 3.7 different physicians during this time

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(Choy et al., 2010). Although the American College of Rheumatology has published diagnostic criteria for FM (Wolfe et al., 2011), these are not widely used in clinical practice, and there remains a knowledge gap regarding the criteria among some health care professionals, particularly in the primary care setting (Choy et al., 2010; Hadker et al., 2011).

According to the National Fibromyalgia Association, an estimated 3% to 6% of the world's population, or more than 200 to 400 million people worldwide, have this chronic condition, with the majority being women (National Fibromyalgia Association, 2016). This chronic disease increases in prevalence with age (Clauw, 2014; Wolfe et al., 2010), and actual prevalence figures are likely to be underrepresented because of late diagnosis or misdiagnosis (Arnold, Clauw, McCarberg, & FibroCollaborative, 2011; Wolfe, Brähler, Hinz, & Häuser, 2013).

Symptoms of Fibromyalgia

People diagnosed with FM suffer from chronic widespread pain and other symptoms that include fatigue, sleep disturbance, morning stiffness, anxiety, depressed mood, impaired cognitive function, and an overall decrease in health-related quality of life (Wolfe et al., 2010). Notable consequences of having FM include an average of one workday missed each week for those who are employed, an average 10% earnings loss, health care costs averaging US\$3,400 to US\$3,600 per year, and 3 to 5 times the indirect health care costs of the general population (Sanchez et al., 2011; Sicras-Mainar et al., 2009; Spaeth, 2009). Using data from the 2012 National Health Interview Survey (NHIS), authors Walitt, Nahin, Katz, Bergman, and Wolfe (2015) found that in the year prior to the NHIS, disability payments were made to 30.2% of those with FM compared with 2.8% without FM ($p < 0.001$), with fewer women (28.1%) than men (32.4%) with FM receiving Social Security disability payments in that year. The foregoing data support FM as being a chronic disease that moves beyond the physical and psychological manifestations of the disease, affecting all aspects of one's life.

Adapting and Coping With Chronic Illness

Generally, adapting and coping with a chronic illness such as FM (Keil, 2004; Zulkosky, 2009) requires that people be able to create meaning in their illness, meaning that often shifts with new information that can affect their identity and self-efficacy (Madden & Sim, 2006). According to self-efficacy theory (Bandura, 1992), efficacy expectations refer to the belief that one can competently cope with a challenging situation and has the ability to affect behavior. Thus, self-efficacy operates as an important cognitive factor in the control of symptoms such as pain, with self-efficacy beliefs helping

to explain many of the behaviors and disabilities of those with persistent symptoms.

The manner in which patients receive their diagnoses and the factors that might be associated with the onset of their symptoms influence how they integrate the diagnosis into their identities. Also, the degree to which they perceive that the information received at the time of diagnosis is complete and provides them with some idea of a predictable disease trajectory can influence self-efficacy, symptom progression, perceived symptom severity, and treatment choices (Cedraschi et al., 2013; Madden & Sim, 2006; Paterson, 2001). The lack of diagnosis-related information often undermines the meaning of the diagnosis itself by conveying a sense of inauthenticity and potentially results in patients' lack of confidence in health care providers' treatment recommendations (Lempp, Hatch, Carville, & Choy, 2009).

Compounding the complex diagnostic process of FM (described earlier) are patients' experiences of not having distinct outward manifestations of this chronic condition or its symptoms. Given the lack of objective biomarkers for a diagnosis of FM and that patients present with symptoms common to other functional somatic syndromes and psychological disorders, those affected tend to view FM as an "invisible disease," a condition that they have to defend to family members, health care providers, and work colleagues (Dennis, Larkin, & Derbyshire, 2013; Juuso, Skär, Olsson, & Söderberg, 2011). Research findings support the idea that many patients correlate the lack of objective, observable symptoms with the lack of support they experience from others in their daily lives (Mannerkorpi & Gard, 2012; Sallinen, Kukkurainen, & Peltokallio, 2011).

The experiences of those diagnosed with FM create situations wherein a diagnosis does not provide a predictable disease progression or standard symptomology as might be seen in other diseases such as chronic kidney disease or chronic obstructive pulmonary disease. To the contrary, those with FM have no common reference point from which to interpret their symptoms or disease-related experiences or from which to integrate their diagnosis into their self-identity (Madden & Sim, 2006; Sallinen et al., 2011). Consequently, these patients experience identity confusion that influences their level of self-efficacy (Madden & Sim, 2006). Because self-efficacy is based on feelings of self-confidence and control, it can be a strong predictor of motivation and behavior change. Research has shown that selected interventions can have an impact on self-efficacy and that changes in one's self-efficacy are associated with changes in behavior. Bradley (1989) observed that researchers using cognitive behavioral interventions encouraged patients with FM to take responsibility for managing their pain and disabilities and to attribute their coping successes to their personal efforts, thus enhancing their sense of self-efficacy.

Table 1. Inclusion and Exclusion Criteria.

| Inclusion Criteria | Exclusion Criteria ^a |
|---------------------------------------|--|
| Physician-diagnosed fibromyalgia | Current use of steroids or use of these drugs within the past 3 months |
| Current age between 18–64 years | Currently pregnant (women) |
| Ability to speak and write in English | |

^aThe two exclusion criteria were relevant only to the quantitative component of the study assessing the immune cells (Taylor et al., 2015) but were necessarily applied to all participants.

Study Background

Underpinning the research team's philosophical position is its belief that what patients perceive, think, and feel about their condition should be accepted as something that is real, exists for them, and is therefore legitimate to study. Also, because only a few researchers using a nursing perspective (Cunningham & Jillings, 2006; Schaefer, 2005; Söderberg, Lundman, & Norberg, 1999) have explored systematically what the diagnosis of FM means to those experiencing its complex symptoms and how these symptoms affect their daily lives, the authors' goal was to fill this gap in the recent literature. The authors brought their perspective to the interpretation of data collected directly from those living with FM in a rural community in a Mid-Atlantic state (United States), gaining insight into the participants' perspectives of FM onset, diagnostic course, and their experiences with this chronic condition. Interpretation of the study findings is grounded, in part, in Lazarus and Folkman's (1984) cognitive approach to coping. This approach involves people's appraisal of the level of stress they are experiencing and the coping strategy to be used based on how they appraise the situation they are facing at the time. The findings provide data that nurses might use to inform their decision making regarding the most appropriate assessments and symptom management strategies for this patient population.

Terminology

Given that the term *rural* is an inexact term that can mean different things to different people, organizations, and governments in different countries, we define rural as it applied to our study population. In comparison with other designated rural areas, our study participants *did not* experience barriers seen in other geographic sections of the United States designated as rural. Specifically, the participants did not experience inability to access care or services such as provider and specialist shortages, limited broadband coverage for telehealth services, or other geographic barriers commonly seen in sparsely populated rural areas. Specifically, the 20 participants in this study lived within a 45- to 60-minute driving distance to an academic medical center. They did not experience the usual social determinants of health that could have an impact on their overall well-being. That is, they all had housing and most lived with at least one other person; their education level was high,

with a mean of 14.5 ± 2.37 years; any unemployment they reported was because of their chronic illness and not because of job unavailability in their geographic area; and they had personal vehicles for transportation, although travel to the medical center can be pre-arranged for a minimal fee through a public regional transit system, if needed.

Method

Purpose and Specific Aims

The purpose of this study was to document the experiences and the meaning-making reported by people living with the chronic condition of FM. The specific aim was to capture through semistructured interviews the overall experiences of people diagnosed with FM.

Design, Sample, and Setting

We used author-developed semistructured interview questions to capture the experiences of people living with FM because we had a specific agenda in terms of the topics that we wanted to cover in the interviews. Of course, the participants' responses determined the kinds of information we obtained and the relative importance of each of the questions. The questions were developed based upon the authors' earlier clinical research study findings along with patient experiences, clinical practice observations, and opinions of experts reported in research literature.

The interviews were one component of a larger study in which the researchers also assessed differences in immune cell populations and symptoms in 20 people with physician-diagnosed FM. Immune cell and symptom data collected from these participants with FM were compared with that of 20 age- and gender-matched healthy controls recruited from this same geographic area (Taylor et al., 2015). Following the academic medical center's Institutional Review Board for Health Sciences Research approval of the study protocol and study materials, the authors recruited the sample of participants using purposive convenience sampling. Potential participants learned about the study from a website of ongoing clinical trials being conducted at the medical center and from study brochures distributed to those who indicated interest in the study. The study inclusion and exclusion criteria are shown in Table 1. Interested

people contacted the study coordinator regarding study participation and, if deemed eligible following the pre-screening process, were scheduled for an in-person informed consent session.

Following completion of the informed consent process, each of the 20 participants with FM took part in a one-time, one-on-one interview lasting between 40 and 60 minutes to discuss living with FM. Including all 20 participants in the interviews was purposefully done to give all participants an opportunity to tell their stories as opposed to interviewing a subset of the participants to the point of data saturation. Although data saturation was reached after interviewing 12 participants, we continued the interviews, permitting all 20 participants to tell their stories. Although the authors collected data for both the quantitative and qualitative arms of the study during the same study visit, the data were analyzed and published separately. One component of quantitative data (reported in Taylor et al., 2015) was the Fibromyalgia Impact Questionnaire (FIQ) scores that are included here to provide the reader a gauge of impairment of the participants' functional status and their perceived health-related quality of life (Bennett, 2005; Burckhardt, Clark, & Bennett, 1991).

Data Collection

Three research team members interviewed the participants, digitally recording their responses. The interviewers sought information regarding the duration of the participants' FM diagnoses and symptoms, what they perceived was happening in their lives at the time of the onset of their symptoms, and to what they attributed symptom onset. Interviewers also asked about the impact of symptoms on participants' personal and social lives and about treatment modalities that they had tried in the past (see online supplementary material [available at <http://gqn.sagepub.com/supplemental>], "Semistructured Interview Questions").

Data Explication and Analysis

The digital audio recordings from the 20 interviews were transcribed (511 pages of transcription) by Accutype Services (Charlottesville, VA), a professional transcription company, and two research team members reviewed the transcriptions for accuracy. The research team members organized, explicated, and interpreted the interview data using qualitative content analysis to identify recurrent, or common, themes (Chenail, 2012; Green & Thorogood, 2009; Hsieh & Shannon, 2005; Saldaña, 2013; Vaismoradi, Turunen, & Bondas, 2013). They read the transcripts and used inductive reasoning to derive a coding scheme and to identify related patterns or themes within the data (Cohen, Kahn, & Steeves, 2000; Gadamer, 2004; Vaismoradi et al., 2013). Organization of the data into "meaningful units" (MUs) facilitated the identification of themes within the data. MUs are manageable passages of text that have been partitioned on the basis of what appears

initially to be one main thought or essential concept (Saldaña, 2013). Qualitative content analysis was used because it went beyond merely extracting content from the interview data to examining meanings, themes, and patterns, allowing the authors to understand in a subjective, yet scientific, manner what the participants were saying in the interviews.

NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2014) was used to organize, manage, and code the data and for text retrieval and node/category manipulation. Specifically, after the interview recordings were transcribed, the initial readings of the data sought to clean the transcription text by eliminating conversational terms such as "you know," "uh," and "like" (Cohen et al., 2000). Tamara Fischer-White, Kate Adelstein, and Maheswari Murugesan coded the transcripts sequentially, a process that helped the team to remain focused and promoted in-depth analysis of each transcript. After reading an entire transcript, these three authors completed a careful reading of each sentence and then divided the text into individual MUs using the participant's own words when possible (Rennie, Phillips, & Quartaro, 1988). Multiple such MUs were read and re-read while comparing these to existing codes. This same process was repeated for each interview. Following this process, the research team created overarching category schemes to unify the participants' experiences into a meaningful whole. The research team met every 2 weeks to compare the content analysis categories, the emerging themes, and to discuss any issues that arose during the process. Because codes are not always mutually exclusive, a piece of text could be assigned to several codes. Groups of codes that expressed the same ideas or phenomena were classified broadly into categories. Last, the research team used focused coding to eliminate, combine, or subdivide coding categories and to look for repeating ideas and larger themes that connected the codes. Ann Taylor and Joel Anderson engaged in debriefing with the three initial coders to ensure coding consistency and confirm their interpretations, including the development of codes and categories and finally the themes, working to achieve 100% agreement in the coding.

Strategies Used to Ensure Methodological Rigor

To ensure methodological rigor and support the utility of the findings from this study, the authors focused on criteria relevant to evaluating qualitative research. Selected criteria were applied to achieving study rigor, including credibility, dependability, and confirmability using specific strategies for each criterion derived from the seminal work of Guba (1981) and discussed in Vaismoradi et al. (2013). Credibility involved, in part, the strategy "member checking" (also known as respondent validation, or feedback) to establish that the data being collected reflected the perspectives of the participants who were providing descriptions of their experiences of living with FM. In applying this strategy, throughout the interview process, the three interviewers validated with each participant what the

interviewer was hearing and understanding from the information provided. These verification strategies helped the researchers to check systematically the data and to maintain the focus of the study. To enhance further the study credibility, the authors identified “meaningful units” (described earlier) to help in developing the study themes from the interview data. Finally, study credibility was addressed through the researchers meeting as a group every 2 weeks to review the transcripts and emerging themes as well as overall study progress. The process of collecting and analyzing the data concurrently also aided in checking and verifying the study findings.

A second criterion applied to achieving study rigor was that of dependability. Because this criterion emphasizes the need to account for the potentially changing context in which the qualitative research study was taking place, the defined study sample, specific enrollment criteria, and geographic area were applied consistently throughout the study; the interviews were conducted by the same three researchers using semistructured interview questions; and the setting itself remained the same throughout the study. To improve further dependability of the data, the three coders maintained personal research diaries and open dialogue, providing opportunities to detect similarities and differences that may have been observed over the course of the short study.

A third criterion the study team used to ensure rigor of the study methodology was that of confirmability, which involved the team members maintaining neutrality with respect to the data. That is, the researchers were attentive to their interests, any bias, and/or motivations, not permitting these to influence the study findings. Two strategies were used in addressing this criterion—audit trail and reflexivity. Regarding the audit trail, the researchers maintained a relatively transparent description of the research steps they took from the beginning of the research project through the development and reporting of the findings, creating a clear description of the research path. Particularly important was the account of the steps taken in the data coding and theme identification, checking and rechecking these data as the process moved forward. The other strategy related to confirmability involved the concept of reflexivity—the researchers’ systematic attention to the research process and what it was yielding throughout the study. The authors shared earlier in the “Study Background” section their beliefs in and value of what patients perceive, think, and feel about their condition and that the authors would be accepting this as something that was real, existed for the participants, and was therefore legitimate to study. Understanding something about the researchers’ perspectives, beliefs, and values is an issue in qualitative research, particularly because of the human research element involved in this type of research. Also, the field notes that the three coders maintained described and interpreted their behaviors and experiences within the context of the research study, thus making them aware of biases and any preconceived assumptions that they might have held. The foregoing

Table 2. Demographic Characteristics.

| Characteristic | Participants (N = 20) |
|-------------------------|----------------------------|
| Age | 49.1 ± 9.56 |
| Sex | |
| Female | 19 (95.0%) |
| Male | 1 (5.0%) |
| Race | |
| White/Caucasian | 16 (80.0%) |
| Black/African American | 4 (20.0%) |
| Ethnicity | |
| Non-Hispanic | 17 (85.0%) |
| No response | 3 (15.0%) |
| Marital/partner status | |
| Married/partnered | 12 (60.0%) |
| Divorced/separated | 5 (25.0%) |
| Single | 3 (15.0%) |
| Years of education | 14.5 ± 2.37 |
| Years with fibromyalgia | 9.63 ± 11.17 ^a |
| FIQ score | 71.20 ± 12.81 ^b |

Notes. FIQ = Fibromyalgia Impact Questionnaire.

^aTime since FM diagnosis ranged from <1 year to 27 years, with no differences in the meaning of the disease reported by those at the ends of the spectrum.

^bFIQ scores ranged from 20 to 100, with 90% (n = 18) of participants’ scores ranging from 60 to 95, that is, high disease impact (Bennett, Bushmakina, Cappelleri, Zlateva, & Sadosky, 2009; Burckhardt, Clark, & Bennett, 1991). FIQ scores reflect the disease severity level. Review of the data for the two participants whose FIQ total score was less than 60 did not reveal anything distinct or different that would set them apart from those who scored higher on the FIQ (high disease impact) nor did they reveal any differences regarding life events surrounding the time of onset of their FM as compared with those in the high disease impact group.

three verification criteria and related strategies contributed to and ensured rigor in this study.

Results

The analysis included a total of 20 participants (19 women and 1 man). Demographic data for the participants are shown in Table 2.

Participants in this study reported major functional and psychosocial losses that they attribute to their chronic FM condition. Nonetheless, these participants were able to identify personal strengths that enhanced their ability to cope with ongoing chronic pain and disability. The five major themes identified within the interview data reveal what the participants were perceiving, thinking, and feeling about living with their chronic condition—losses: what FM has stolen from me, fear and uncertainty, impact of stress, stigma associated with FM, and coping through courage. Each theme reflects an important component of FM as it relates to quality of life for these participants. The data collected include both consequences of the disease that reduce quality of life and coping strategies the participants used to deal with the losses

and challenges associated with FM. The participants' preoccupation with their chronic condition reportedly affected their lives in many ways. In the following paragraphs, the authors present each of the five themes and, in turn, support the description of each with representative quotations from the participants followed by a brief discussion of the theme. To protect confidentiality, we have assigned pseudonyms to participants who are quoted in this article.

Themes

Losses: What FM stole from me—"I can't do that anymore." Each of the 20 participants described the many losses that they experienced because of their FM. They identified ways in which FM changed their lives, citing various activities that they no longer could do. They related limiting social, family, and work activities because of fatigue and chronic pain or the risk of these symptoms. Limiting these activities left them feeling as if FM had stolen from them opportunities to engage in social, family, and work-related pleasures. Betty, who recently had stopped working outside the home, described the trade-off associated with working and FM symptom severity, saying, "If I work hard today, I'm going to hurt tomorrow, but I'm going to work hard today anyway."

Each of the 20 participants discussed or at least made reference to the challenges they had experienced making plans with family and friends. Camille noted, "What bothers me most is [that] it's very difficult to make plans because I don't know how I'm gonna be that day."

In addition to challenges in making plans with friends and family, these participants described feeling too tired to engage in previously pleasurable activities such as gardening, bowling, camping, or being active with their children or grandchildren, blaming FM for stealing these pleasures from them. Sharing difficulties experienced when interacting with grandchildren and friends, Tyler stated,

Well, I was going to say I would like to be more [physically] active with the boys than I am. . . . I haven't played golf in a year and a half probably. And so with that it's harder getting together with your friends. . . . It's not that I couldn't play [golf]; it just kinda wears me down.

The women ($n = 19$) also described giving up their roles as caregivers for family members and friends. Not being able to perform daily household chores was discouraging to them, and several participants became tearful when discussing this limitation. Describing the ways in which she previously helped her elderly aunt, Karen explained, "I would clean her apartment, change her linens, wash her clothes, clean the windows to her balcony, scrub the kitchen floor, all within a weekend. I can't do that anymore."

Loss of independence was particularly difficult and perceived as unfair by the younger participants, who strongly expressed that they should be able to take care of themselves

and their families. Joan, the youngest of the participants, stated, "I'm only 25 years old and I feel like I can't even do the dishes, which is very depressing."

For all of the participants, the loss that they felt most was that of self-identity. Their FM-related symptoms made spending time with their families, engaging in their hobbies, and caring for others challenging; these were activities that prior to the onset of FM were central to their self-definition. Adjusting to being the care recipient instead of the caregiver, missing outings with friends, and not being able to do their jobs forced these participants to define new parameters for their lives. Karen said tearfully,

I used to pride myself on my work, [that is] being able to get everything completed, being able . . . to do extra tasks that were unassigned, [even] my housework at home. If I get up one morning and I decide, "Oh, I'm going to vacuum today," I [find that] I can't vacuum or mop in the same day because I just can't do it. I have to go lay down.

The participants stated in many different ways that they wished they could simply go back to their lives before the onset of their FM symptoms to enjoy active lives, go out with friends, care for their families, and participate in all the activities in which they used to engage. Karen summed up the sentiments of the other participants, saying, "I just want to be the person I used to be." The cumulative disease-related losses described by the participants resulted in them bringing their FM condition to the forefront of their daily lives.

Fear and uncertainty—"Your downhill slide." For the 18 participants who had been suffering from vague and undefined symptoms for years, the definitive diagnosis of FM came as a relief. Regarding her diagnosis, Gwen, who had been suffering pain and debilitating fatigue for months, noted, "She [the physician] took some tests and said, 'No, you don't have Sjogren's. . . . you have fibromyalgia.' And she put me on Lyrica . . . and the medicine finally helped me." Betty described her reaction to receiving her diagnosis of FM as follows: "My initial reaction [was] I'm relieved to find out the explanation [be]cause a lot of people just think you imagine. . . . It helps me to understand what I'm dealing with when the pain comes." The diagnosis, however, carries with it uncertainty about the progression of the disease and fear and worry about the future.

While 14 of the 20 participants found some treatments such as prescription pain medications, acupuncture, and relaxation techniques helpful, all 20 participants stated that they were aware that no cure is currently available for FM. The functional and social losses that they experienced as a result of FM-related pain and fatigue were further expressed as a fear of and uncertainty about their future. Carol, who was in her 50s, said,

Knowing what I'm facing as I age normally is enough to make you think. . . . When you put something like this [FM] on top of

it, it certainly gives you a whole added reason to worry about what you're going to face and how it [might] combine with other things. . . . I fear I'll end up in a wheelchair sooner than I should be in one.

All 20 participants spoke of the symptoms and disease progression experienced by those with FM, and 14 of them explicitly noted how observing FM in others reinforced their feelings of fear and uncertainty. Pam, who had been living with FM for 12 years, stated, "I [look] at people with fibromyalgia and listen to what they say [and] I think, 'Oh, my goodness, I hope that mine does not get that bad.'"

For those who attended support group meetings either in person or online, the meetings elicited mixed emotions. Those who sought out others with FM found some comfort in knowing that they were not alone in their struggles. However, interacting with others with FM, particularly those with more progressed disease, increased concerns about their own disease progression. Carol described her concerns, saying, "A couple of other people [who] I know have it [FM]. One of them is on full disability, which terrifies me. I don't ever want to be in the situation where I could be facing something like that."

In addition to worrying about the progression of their disease and the worsening of their disabilities, the participants worried about the long-term side effects of the many medications they had tried and worried that they would never get control of their pain. These participants also were working through their fears of mortality. Carol quietly said, "You think a lot about your own mortality and your downhill slide." In contrast, Diane described her experiences with an online (Facebook) support group, noting, "We stay in contact with each other . . . and we kinda chime in with people all over the world . . . and support each other." Both Mishel (1999) and Paterson (2001) have suggested that the uncertainty such as that evident in the above participants' statements should be viewed as a dynamic perception that can change over time and fluctuate with the severity levels of participants' symptoms.

The impact of stress—"I just kind of stuff it." Each of the 20 participants either mentioned or discussed in detail the relationship they perceived between stress and FM. They all associated the onset of their symptoms with a particularly stressful life event or series of stressful events. Describing the stress she experienced at work combined with a family tragedy at the time of her diagnosis, Karen, who had recently stopped working outside of her home, noted, "I believe that stress is a big factor with fibromyalgia and the Raynaud's [disease] because I had never in my life been under this much stress at one time and then all of a sudden everything hit me." The participants described their symptoms worsening in times of stress and improving as the stress in their lives decreased. Paterson (2001) describes such shifting perspectives as reflecting the individualization of experiences that

those with chronic illness have, revealing their situations and needs at the time.

The FM diagnosis itself also caused a great deal of stress in the lives of the participants. Feelings of worry about the future and not being able to accomplish simple tasks led to high levels of stress. As Linda noted, "I'm used to doing things at level A. When I can't do things at level A, I get stressed out and then I get really anxious and that sort of kicks in the stress response."

The cycle of stress-related symptoms became a burden to those participants who struggled to find ways to reduce stress in their daily lives. Interview findings reveal that stress was both a precursor and a sustaining feature of FM-related symptoms. Regarding the cycle of stress and symptoms, Cathy said, "I know that stress can cause a lot of symptoms physically. I've been under stress for so long, it's as if I almost don't remember what it was like not [to] be stressed."

A commonality among 18 of the participants was the tendency to internalize their feelings of being stressed. Already feeling guilty and dependent, they were reluctant to share with their family members the level of stress they were experiencing. Rather, these participants expressed that they felt they should shield their loved ones from the extent of their distress, especially because they believe that they already require so much help from family and friends. Referring to her own tendency to shy away from discussing her stress with her friends and family for fear of burdening them, Carol remarked, "I don't externalize my stress. I kind of stuff it [internally]."

Fifteen of the participants described their stress generally as resulting from a constellation of events that the authors interpret as consisting of a stimulus (a stressor) that precipitates a reaction in their brains (the participants' perceptions of the stress) that, in turn, activates their physiological body systems (the stress response). Taylor, Goehler, Galper, Innes, and Bourguignon (2010) describe the bidirectional "top-down and bottom-up" interactions between the brain and peripheral tissues that contribute to both mental and physical health, mechanisms that were likely at play in the stressed participants in this study. These participants likely activated their hypothalamic-pituitary-adrenal axis during stressful times. The stress hormones that were released affect virtually all cells and tissues in their bodies, giving rise to the symptoms the participants experienced. However, given that some people can generate and experience psychological stress in the absence of external stressors, the resulting physiological stress response can have the same deleterious effects, including significant effects on immune cell distribution and function (described in Taylor et al., 2015).

The stigma associated with FM—"They just won't understand." Adding to the existing stress caused by the symptoms of FM, 17 of the 20 participants discussed the diagnosis-related stigma, including the insensitivity of health care providers and their employers, particularly relating to

the invisibility of FM symptoms. These participants noted that because they generally appear well, many people with whom they interact are skeptical about whether or not there is anything wrong with them. Linda explained,

My mother and I talked about this. When you need a hip replacement, you go from A to B to C and you know kind of what's going to go on. And everybody kind of respects what you're going through and knows how to handle it. I think what's hard . . . is that no one here really understands [what I am telling them]—I haven't found a physician yet [who] recognizes it [FM] as a legitimate thing.

Karen described feeling like a “piece of discarded trash” when she lost her job after being diagnosed with FM. She perceived that her employer was firing her because of her chronic illness, although the employer claimed that she [Karen] simply was no longer well suited for the position she held.

Ten of the 20 participants spoke of physicians who told them that their symptoms were psychological; more specifically, five reported having been told that their symptoms were “all in their heads,” and 17 of the 20 reported that they have to justify their symptoms to others around them. Three stated they are embarrassed by having to take pills every day to control their symptoms and worry that their chronic pain will be perceived by others as a weakness. Fifteen participants noted, too, that they have identified silence as a means of coping with this embarrassment and only share their FM-related experiences with a trusted few. Joan, an unmarried mother who has been challenged to find meaningful relationships, summed up her position when she said, “So I don't talk about it [FM] to a lot of people [be]cause they just won't understand.”

Evident in these participants' comments is the fact that having a chronic illness such as FM brings suffering beyond the physical symptoms. They struggle with the social meaning of the condition and their feelings of being stigmatized. Perhaps the most important step in reducing the stigma expressed by those with FM is identifying health care professionals who are knowledgeable about this chronic condition and can provide the support and information people with this chronic illness need.

Coping through courage—“*Instead of focusing on the pain, I try to display courage.*” Regardless of the pain, fatigue, worry, stress, loss, and fear, 19 of the 20 participants stated that they find the inner strength and the courage to face each day. Several participants also stated that they rely on optimism, faith, and humor to help them cope. They spoke, too, of finding an appreciation for life despite their circumstances. Carol reflected,

I am definitely a glass half-full person. I have a great sense of humor. I have an appreciation for life and the world and so I put myself in situations and around people [who] are uplifting and make me happy. I just don't dwell on the negatives.

In a similar manner, Theresa explained her attitude in dealing with her FM diagnosis:

I try not to be too depressed because I think about other people who have a lot worse situations. And even though my condition is not to be desired either, I'm alive . . . I'm not blind . . . I'm not crippled, so I try to have a positive outlook on it . . . I try.

Several participants conceptualized living with FM as a battle that they were determined to win, refusing to let the disease prevent them from living their lives as fully as possible. Engaging the disease by continuing to work at their jobs despite debilitating symptoms was defined as one of the measures of winning. Again, Carol, who holds a high level position in her workplace, noted, “I will be crawling on the ground on my way to work before I give up and say, ‘That's it, you win, fibromyalgia. Take me. I'm yours.’” For these participants, beating FM meant being able to be happy in the face of difficult circumstances, to find small pleasures in their day-to-day lives. For several other participants, it meant hanging on to pieces of their earlier lives whether through work or continuing aspects of caregiving. When asked how she coped with the stress and chronic pain that she had described, Diane, who works as a professional caregiver, responded that she tries to focus on something else or helping someone else instead of focusing on the pain.

The interview data revealed, too, that FM becomes the focal point for those who suffer daily with its symptoms and limitations. When the participants were no longer able to engage in activities that previously gave meaning to their days, they struggled to maintain a sense of self. Carol's comment reflects what others expressed, too, when she stated succinctly, “I try really hard not to make it [FM] a part of who I am.” Without effective treatments and no known cure, in general, coping with this chronic condition and its symptoms is the participants' primary goal in their daily struggle for improved health-related quality of life.

Discussion

The aim of this study was to describe the experiences of 20 people living with the chronic illness FM. The qualitative study design allowed these participants to tell their stories from their perspectives, relating to the nurse researchers how they deal with this chronic condition. The study results reveal that the participants have experienced losses they attribute to their FM-related condition. These losses include jobs, hobbies, and participation in social activities with friends and family. The additive effect of these losses led to a fundamental redefinition of their pre-symptom onset self-identity. The loss of self-identity, a major concern of those with chronic conditions (Lazarus & Folkman, 1984), is documented in qualitative research findings (Sells et al., 2009). Consistent with the findings reported in this article, authors of another study (Wuytack & Miller, 2011) reported that feelings of uselessness and identity loss resulted from limitations that study participants attributed to their FM-related symptoms, particularly among those who were no longer able to work.

The shifting perspectives model of chronic illness (Paterson, 2001) can help nurses and other health care professionals in understanding that selected chronically ill people do not progress along an illness continuum. Instead, they are constantly challenged to integrate and make sense of their disease experiences in relation to self. To this end, they progress along a non-linear path with their perspectives moving them back and forth from what Paterson describes as thinking about illness to thinking about what it would be like to be well again. In the case of the FM participants, when they spoke of their desire to return to the lives that they once knew, we interpreted this to mean that they were bringing into the moment their perspectives of earlier days of wellness and what their lives were like before FM. Important here is that the diagnosis of FM or the onset of new condition-related symptoms forces the person to attend to the illness, to attempt to understand it, and to come to terms with it. However, FM has so few objective indicators of what is occurring within the body, those with FM find themselves focusing on a description of outwardly invisible symptoms to convey to others that their illness is real.

Also, because actual losses and perceived loss, including occupational and social losses, compromise self-identity and lead to feelings of stigmatization (Lazarus & Folkman, 1984), this forces the person to consider his or her life from the standpoint of pre- and post-FM symptom onset (Lempp et al., 2009) or perhaps to shift his or her perspective from a level of wellness to that of illness as described by Paterson (2001). Given this situation, a diagnosis of FM and its associated clinical features threaten not only people's identities but also their dignities as they grapple with the loss of independence and freedom generally associated with health (Lazarus & Folkman, 1984; Söderberg et al., 1999).

Difficulties attendant to losses, distress, and stigma associated with a diagnosis of FM and its somatic symptoms led participants to share also their perspectives on their poor health-related quality of life. All of the participants attributed onset of their FM-related symptoms to major life stressors or events. They frequently experienced symptom flare-ups from perceived increases in their daily stressors. This group of participants contends that the internal stressors of identity loss and identity change, as well as the external stressors of having a chronic condition, are sources of increased daily stress. They shared that they have two coping options: either to (a) justify continually their FM diagnosis and its associated symptoms or (b) keep their diagnosis and symptoms to themselves. Either option results in increased levels of stress, which is considered a primary triggering and sustaining factor in FM. According to Lazarus and Folkman (1984), those who view themselves in unchangeable conditions tend to adopt emotion-focused coping strategies. They try to reduce the negative emotional responses associated with their stress because this might be the only realistic option they see when the source of their stress is beyond their control and resources,

leaving them feeling more stressed. Therefore, the extent of control that people with FM perceive they have is an important factor to consider when assessing the resources available to them to deal with their illness. This information is particularly germane to nurses when choosing appropriate symptom self-management interventions (Bazzichi, Sernissi, Consensi, Giacomelli, & Sarzi-Puttini, 2011; Bellato et al., 2012; Bennett, Jones, Turk, Russell, & Matallana, 2007; Clauw, 2007).

To avoid subjecting themselves to the skepticism of those around them and not be seen as a burden, those diagnosed with FM often deal in isolation and silence with the fear and uncertainty of a yet-to-be-fully-defined chronic illness (Kengen Traska, Rutledge, Mouttapa, Weiss, & Aquino, 2012; Sallinen et al., 2011). This influences the level of adaptation to their chronic condition (Johnson, Zautra, & Davis, 2006). Ramiro et al. (2014) report that women with FM are more likely to experience anxiety and depression as a result of stress than age-matched peers without FM. This association leads to a decreased quality of life and diminished functional abilities (Homann et al., 2012). Given the undeniable link between stress and illness (Wolfe, Walitt, & Häuser, 2014), FM itself increases perceived stressors in a person's life, thus increasing both the number and severity of symptoms.

Study Strengths and Limitations

Although a strength of this study is that the findings are based on rich interview data from participants with physician-diagnosed FM, the participants were primarily women living in a rural setting in a Mid-Atlantic state in the United States, which could limit the generalizability, or transferability, of the study findings. From the beginning of this study, the research team members worked under the assumption that the study findings would be descriptive in nature, representing the perspectives of the particular group of patients living with the chronic condition FM in a specified rural setting. However, the authors provide background information about the study participants and their level of symptom severity, the context for the research, and the variables related to the rurality of the study setting, providing adequate information for transferability judgments to be made by others.

The potential for biases related to participant self-selection could exist, thus limiting transferability. However, looking at the data per se rather than the study participants themselves, the authors believe that the content of the interviews and the participants' behaviors are typical of the lives of all 20 participants enrolled in this study.

Clinical Implications

The experience of living with FM and what it means to those affected presents challenges. Not the least of these is locating physicians, nurse practitioners, and other providers who have



Figure 1. Linkage of study concepts, study themes, and theoretical models.

Note. Two frameworks are used to show the linkages among the study concepts and themes (blue boxes) in relation to the person with fibromyalgia, including (a) an adaptation of Paterson's (2001) shifting perspectives model of chronic illness (orange boxes) and (b) Lazarus and Folkman's (1984) ways of coping model (green boxes). We present information in the fashion of concentric circles to emphasize the interconnectedness between the study themes and the constructs of the two models. Paterson's shifting perspectives model shows how the participants assess their chronic condition. The participants' ways of coping are illustrated within Lazarus and Folkman's ways of coping model. Our study model demonstrates a multidirectional flow, suggesting the influence of one set of elements upon another.

the training, knowledge, and perspective that support their ultimate roles in relieving unnecessary suffering. The results of the current study and those of earlier studies suggest the importance of health care providers' understanding the symptoms associated with FM and how these affect all aspects of patients' lives. In particular, for practitioners working in non-acute care settings, the participants' comments underscore the importance of actively listening to patients' stories to capture the full impact of their FM and to identify those approaches that can be implemented as symptom self-management strategies. Given the link between distress and symptom severity experienced by those suffering from FM, low-cost and readily accessible stress management techniques within the context of what Kaptchuk and Miller (2015) describe as supportive, attentive, and empathic health care "can predispose patients toward reduced symptom severity and lessened reactivity to [their] underlying pathophysiology" (p. 9).

To address feelings associated with identity loss, it might be helpful to provide patients with strategies that support them in regaining some function while participating in activities that give meaning and purpose to their lives. The focus of these strategies might incorporate therapies that enhance pain management and improve restorative sleep. Examples include breath techniques and selected restorative yoga poses or other gentle yoga poses appropriate for the person's limitations and that, once learned, can be practiced independently at home to ensure sustainability of the practice (Mist, Firestone, & Jones, 2013; Taylor et al., 2015). In addition, apart from drug therapy to relieve patients' symptoms, clinicians can be therapeutic simply through the manner in which they relate to those with FM.

Figure 1 provides a model for linking the concepts and themes in the present study. Two frameworks (an adaptation of Paterson's [2001] shifting perspectives model of chronic illness and the Lazarus and Folkman's [1984] ways of coping

model) are used to show these linkages in relation to the persons with FM enrolled in this study. Using our model, the nurse can identify information that can be useful in planning nursing interventions for selected patients with FM.

Although some of these participants tended to use emotion-focused coping strategies at times, some were able to use problem-focused coping strategies, including humor, optimism, and helping others, to increase resilience and buffer their symptoms of depression and anxiety (Cho & Oh, 2011; D'raven, Moliver, & Thompson, 2015; Layous, Chancellor, & Lyubomirsky, 2014; Wurm & Benyamini, 2014). Others used passive coping, including withholding information about their condition, thereby limiting negative feedback from those around them. Because coping strategies aim to alter, manage, or foster tolerance of stressful situations, coping strategies used by those with chronic illnesses should not be assessed as good or bad. Rather, an emphasis on long-term effects and the promotion of coping mechanisms foster an increase in health-related quality of life for those diagnosed with FM, helping them to enjoy activities that bring meaning to their lives. Further research is needed to explore interventions designed to increase positive emotions and resilience in this patient population.

Conclusion

Study participants provided descriptive interview data that revealed major functional and psychosocial losses that they attributed to their chronic conditions. The findings add to the growing body of nursing knowledge to guide care providers in identifying symptom self-management approaches for this population. Our description of the “patient experience” for a selected group of patients living with FM highlights their perceptions of their health care needs and desire for safe, patient-centered quality care. To be most supportive of patients diagnosed with FM, starting with their perceptions can lead to improved engagement between patients, nurses, and other health care professionals, resulting in better patient outcomes. More research is needed to study the potential effectiveness of complementary health approaches and symptom self-management strategies to help these patients regain the ability to participate more fully in their lives.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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