

MUSCULOSKELETAL SECTION

Factors in the Building of Effective Patient–Provider Relationships in the Context of Fibromyalgia

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Abstract

Objective. Fibromyalgia patients face particular challenges in building relationships with health care providers. In this study, we examine, from patients' perspectives, factors that influence the formation of effective patient–provider relationships. **Design.** This research employed a qualitative approach to analyze data collected from a study that employed semi-structured interviews. **Methods.** Multiple methods were used to recruit 23 fibromyalgia patients for interviews. Semistructured interviews were conducted to explore how participants' information behaviors, including their communication with and relationships to providers, changed over time. The interview data were analyzed using a qualitative analytic method based on interpretative phenomenological analysis and constructivist grounded theory. **Results.** We identified three important factors that influenced the building of effective relationships: patients and providers' interactions involving information, identifying health care providers that fit patients' needs, and realizing shared responsibilities. With regard to information, we described three important themes: information gaps, providers as educators/facilitators, and collaborative information behavior. **Conclusions.** Understanding of the key elements of relationship development between patients and providers can be utilized in various ways to improve clinical care. First, the knowledge gained in this study can inform the design of patient education materials that assist patients to identify providers that fit their needs, prepare for consultations, and develop realistic expectations for providers. The findings of this study can also inform the design of resources and tools to enable clinicians to communicate and relate better with their patients.

Key Words: Patient–Provider Relationship; Patient–Provider Communication; Information Interactions; Collaborative Information Seeking; Collaborative Problem Solving; Fibromyalgia

Introduction

Fibromyalgia syndrome is a chronic, noninflammatory condition that is characterized by musculoskeletal pain, impaired cognitive function, disturbed sleep, fatigue, and depressed mood without a well-defined underlying organic disease [1–3]. Estimates of the prevalence of fibromyalgia differ worldwide, but generally vary between 2% and 5% [4–7], and the experience of fibromyalgia is persistent, with patients reporting similar symptoms a decade or more later [8,9]. Chronic pain has been identified as the key symptom that influences many aspects of patients' lives, including their personal and professional relationships, physical activity, work, and social commitments [10].

Patients who suffer from fibromyalgia often experience difficulties in their interactions with their

physicians. At the outset, fibromyalgia patients often experience a lack of understanding from medical practitioners and others around them [11–15]. They have reported feeling dismissed and disbelieved [15–17]. Research analyzing online discussion content by fibromyalgia patients has also reported that patients expressed frustration at doctors and counseled each other to switch to more understanding doctors [16].

Many of the difficulties that fibromyalgia patients experience have also been reported by patients with chronic pain. Chronic pain patients are often labeled as hypochondriacs, avoided, hurried by physicians, and given inadequate time to discuss their problems [18]. Other patients have reported feeling forced to be overassertive and look sickly in order to be taken seriously [19] and feeling like their physicians did not understand their

feelings toward taking medication and just assumed they were seeking out more prescriptions [20].

Tensions in relationships may also arise from contrasting needs and desires in patients' and primary care practitioners' perceived roles [21], including patients with chronic pain and health care providers having opposing attitudes and goals, with patients seeking "to be understood as individuals" and have their pain concerns legitimized, while their health care providers may place a greater emphasis on diagnosis and treatment [22]. There may also be differences in terms of patients' and providers' orientation toward illness (biomechanical vs biopsychosocial), and treatment goals and expectations [23].

There are other factors that may exacerbate issues that patients experience as they seek out help from health care providers. For example, receiving a diagnosis can be one of the biggest obstacles to receiving treatment. Survey research has reported that a significant portion of physicians, including both primary care providers and specialists, do not have adequate knowledge of the fibromyalgia diagnostic criteria [24,25], and that up to 54% of physicians experience difficulty diagnosing it [24].

Fibromyalgia patients also experience the need for information. Patients are uncertain about the definition of the syndrome and the symptoms that are part of fibromyalgia [11]. Fibromyalgia patients seek information on a diverse set of topics, including symptom management, treatments, medications, the cause of fibromyalgia, health outcomes, methods to cope, and impact on daily life [26–28]. Although the majority prefer acquiring information face-to-face from providers, a significant proportion of participants seek information from different sources because of a lack of information, indistinct information, or lack of attention from health care providers.

In this article, we take a qualitative approach to examining patient–provider interactions using data that were collected during an interview study focused on fibromyalgia patients' illness journeys. Similar to the findings reported in this literature review, study participants shared stories of negative interactions with physicians, particularly early in their illness journeys. However, in contrast to this literature, study participants were eventually successful in building long-term relationships with their physicians. We explore, from the patient's perspective, key factors that influenced the formation of these relationships: information interactions, finding providers, and realizing shared responsibilities.

Methods

Sample and Recruitment

Multiple recruitment mechanisms were used to recruit a convenience sample that self-identified as having fibromyalgia ($N = 23$). The recruitment mechanisms included an email contact list from a previous survey [27], a university listserv, face-to-face support groups, health-

related discussion forums, and Twitter. A recruitment goal was established to recruit a sample that was diverse in terms of three characteristics: age (<47 years and ≥ 47 years), illness duration (≤ 4 years and >4 years), and social media participation style (nonuser/lurker, infrequent participator, active participator), with substantive representation in each of the subcategories per category. Though the focus of this study was on patient–provider interactions rather than health, the Revised Fibromyalgia Impact Questionnaire was used as a brief assessment of participants' illness severity [29].

Interviews

Data for this analysis were collected as part of a study on the relationship of information behavior, knowledge, and communication over time in fibromyalgia patients. The results of this study are reported in Chen [30]. Because the study examined change in information behaviors and knowledge representations over time, participants were also asked to draw a timeline representing their illness journey. Each participant was interviewed about their health history, information seeking and use, and social media participation. The first author conducted all of the interviews. The first interview focused on participants' health history and information seeking and use, which included their communication with their health care providers. Participants were asked about the information needs that they had, the information they encountered, and the information that they would have liked to have, as well as their interactions with health care practitioners. The interview followed a semistructured format in which the interviewer encouraged participants to elaborate on the information sources and encounters they had, which led to extensive discussion of patients' interactions with their providers and facilitated the present analysis. The interview guide is provided in Box A1.

The second interview was used to explore participants' social media participation histories. As this paper focuses on thematic analysis of the interview content relating to patient–provider communication, the second interview will not be discussed in further depth. The mean total interview time per participant was two hours and 26 minutes.

Data Analysis

Interview transcripts served as the basis for this analysis. The content was analyzed using Atlas.ti, version 1.0.1, by the first author. The qualitative analytic procedure was informed by two approaches: interpretative phenomenological analysis and constructivist grounded theory. The first step of our analytic procedure involved line-by-line coding. In grounded theory methodology, line-by-line coding ensures that the researcher stays close to the data, verifies and saturates categories, and minimizes the potential for missing categories [31,32]. The

constant comparative method, which involves constant comparisons of instances that have been assigned the same category and categories with one another, was used to ensure systematicity in the analytic process [31,33], and care was taken to ensure that the categories were well developed and that there was conceptual density [34]. The codes were conceptualized as a nested hierarchy, as is customary in grounded theory [35]. In this aspect, our analytic method also inherits from interpretative phenomenological analysis, in which the codes are arranged in themes and subthemes [36]. This hierarchical structure facilitated both organization of the codes and consideration of whether there were gaps in the conceptualization of categories. Lastly, it can be used as a tool to facilitate scrutiny of codes, clarify research thinking, and map research activities, among other uses [37,38]. In this study, memos were used to consider how codes relating to patient–provider interactions were related, organize them, and consider what gaps might still exist in the codes and categories.

The primary aim of interpretative phenomenological analysis is to explore how participants make sense of their world and focuses on participants' interpretations of an object or event [39,40]. Grounded theory focuses on how social and psychological processes occur in a given environment or situation [41,42]. Our analytic procedure was based on these two approaches because lived experience, as well as social interactions and context, were important foci for the study.

To protect the identities of the participants, each participant was assigned an identification number. There were four pilot participants; thus, the 23 participants in the study will be referred to as P05-P27. The study protocol was approved by the Institutional Review Board. All participants gave written informed consent for their data to be used in publications at the time of the interview.

Results

Sample

The majority of the sample was comprised of white women, which is consistent with prior studies relating to fibromyalgia involving larger samples [9,43]. The participants resided in nine different states, Washington, DC, and Australia. The use of multiple recruitment methods led to a sample that varied in terms of age (range = 21–79 years) and illness duration (range = 1–58 years), though those with short illness durations were underrepresented. The sample also varied widely in terms of illness severity. Sample characteristics are depicted in Table 1, and a brief synopsis of each participant's age and health history appears in Table A2.

Health care practitioners played a prominent role in the interviews of all participants. There was great diversity in the types of practitioners that were seen. In terms of allopathic traditions, patients generally saw general

Table 1. Sample characteristics

Characteristic	Category	No.	%
Age, y	21–30	4	17.4
	31–40	4	17.4
	41–50	2	8.7
	51–60	7	30.4
	61–70	5	21.7
	71–80	1	4.3
Gender	Female	22	95.7
	Male	1	4.3
Race/Ethnicity	White	20	87.0
	Black	2	8.7
	Asian	1	4.3
Education	Some college	2	8.7
	2- or 4-y college degree in progress	1	4.3
	2- or 4-y college degree	8	34.8
	Graduate degree	11	47.8
	Graduate degree in progress	1	4.3
Employment status*	Student	11	47.8
	Employed full-time	11	47.8
	Not employed	3	13.0
	Retired	9	39.1
Received disability	Yes	8	34.8
	No	15	65.2
Illness duration, y	≤4	3	13.0
	>4	20	87.0
Social media participation	Nonuser/lurker [†]	9	39.1
	Infrequent participator	5	21.7
	Frequent participator	9	39.1

*Participants may belong to more than one category.

[†]The term “lurker” refers to a person who reads social media content but does not author content.

practitioners, rheumatologists, and neurologists. Alternative medical practitioners included chiropractors, acupuncturists, massage therapists, physical therapists, and naturopaths. Participants usually established long-term relationships with multiple health care practitioners, and many assembled a team of health care practitioners that they relied on. For some, this included a team of primarily allopathic practitioners, and for others, a combination of practitioners of various traditions and perspectives, including allopathic, alternative, and integrative.

Information Interactions

In patient–provider communication, information plays an important role. Patients both experienced gaps in information, as well as created gaps, in their interactions with providers. These gaps were not conducive to building successful relationships. When successful

Table 2. Characteristics of patient–provider interactions and practice implications

Theme	Observed Phenomena	Practice Implications
Information interactions		
Information gaps	<ul style="list-style-type: none"> • Lack of respect from providers • Lack of clear answers • Lack of progress in treatment • Lack of information led to patients seeking their own information to bring to providers • Patients withhold their diagnosis from providers to obtain more information 	<ul style="list-style-type: none"> • Patients can make an effort to present information to providers • Providers should create a space where patients feel that they are being respected and their information needs are being addressed
Providers and educators and facilitators	<ul style="list-style-type: none"> • Providers refer patients to additional information sources 	<ul style="list-style-type: none"> • Providing practitioners with consumer-friendly information sources could be helpful • Affirming the value that providers offer in sharing and educating could instill a sense of purpose
Collaborative information seeking and problem solving	<ul style="list-style-type: none"> • Use of multiple information sources • Process is dialogic (may involve multiple information interactions between the clinician and the patient and occur over multiple clinic visits) • Multiple providers deal with different aspects of condition 	<ul style="list-style-type: none"> • Physician should be open to information that patients bring into the consultation • Efforts should be made to facilitate continuity of information exchange over time, including the provision of digital tools
Developing the patient–provider relationship		
Identifying health care providers	<ul style="list-style-type: none"> • Finding and building relationships with trusted providers took a long time • Patients identified criteria for selecting providers • Patients developed realistic expectations • Patients learned how to utilize consultation time effectively 	<ul style="list-style-type: none"> • Patients can receive assistance on identification and selection of providers • Providers could be made aware of patients' expectations
Sharing responsibilities		<ul style="list-style-type: none"> • Both patient and provider should be respectful of each other's knowledge • Patients could be provided with information about how to prepare for their appointment

relationships were established, participants were enormously appreciative of the role that providers played as educators and facilitators. Patients and providers also worked together in collaborative information seeking and problem solving. We discuss each in turn.

Information Gaps

In this study, participants spoke of two main types of communication gaps: patients experiencing frustration with the lack of information from practitioners and patients' withholding of information. When asked about information that they received from practitioners, many said that earlier in their journey, they did not receive much information. P05 said, "It was a very frustrating time, because nobody could give me clear answers. They were like, oh, we think it's fibro, and once they tell you it's fibromyalgia, then that's it. . . . They were like, okay, that's it. Don't have much to do for you." Some participants reported being told that their symptoms were all in their heads (e.g., P06 and P12). Many participants became frustrated at being prescribed pain medications and not receiving explanations for what they were experiencing. For example, P24 said, "I was like, I don't want to mess with those hard pain meds. I just don't. And they

[pain management providers] couldn't understand that, I guess, because they have so many people who come to them just wanting the meds. I'm like I don't just want you to mask it. I want to know what the problem is."

There were situations in which participants felt that there was information that they could have been told that would have made their journey easier. For example, two participants mentioned that they were prescribed antidepressants for pain, and they did not really understand why. In another case, a participant discovered that her physician had withheld his suspicion that she had fibromyalgia. She had gone to a chiropractor, who suggested that she might have fibromyalgia:

I said to the general physician, "This chiropractor thinks I have fibromyalgia." And he said, "I do too. I just did not want to make that diagnosis because I was afraid it would impact your health insurance in the future." So that was really shocking to me, and I kind of understood later what he was talking about, but I still didn't think that was right at all not to tell me what he thought my problem was. (P06)

Conversely, P10, who had been diagnosed with both fibromyalgia and psoriatic arthritis at different times,

related her experience of being diagnosed with psoriatic arthritis: “When I was diagnosed. . . he called me at home, personally. He also talked to my parents, but he actually talked to me on the phone, and I went into his office and we talked. Face-to-face, which I think is an appropriate thing to do, you know.”

There were cases in which the lack of information spurred participants into action. P22 became fed up with the lack of progress in terms of her health situation:

I want to move on. I either want to be better or at least understand what the problem is and what can be done about it, not this holding pattern where everything seems to be just piling up, and we’re getting nowhere. . . . There’s a lot of confusion, a lot of information coming and going, and nothing is happening. It’s just sort of destruction. (P22)

She decided to go see an orthopedic specialist that she had seen for a long time for advice, who in turn referred her to a rheumatologist who diagnosed her with fibromyalgia. She called this a “green light” because it confirmed what she already thought she had. P13 said that the lack of progress in his medical consultations led him and his mother to actively seek information: “We were both just digging around because the doctors were being completely unhelpful. So we were trying to find out what’s actually going on so we can be prepared with options to suggest to the doctor when we actually go there.”

The previous examples describe situations in which participants described becoming more proactive and engaged in seeking answers due to information gaps. There were also situations in which information gaps were strategically created by patients in order to get at answers to their questions. For example, some participants withheld that they had been diagnosed with fibromyalgia in selected clinical interactions. Often, this was because participants perceived that fibromyalgia had a tendency to become the physician’s explanation for a phenomenon that the patient experienced, and the patient wanted a clearer medical explanation. For example, when P12 consulted a physician about some health problems she was experiencing, the explanation turned out to be hypoglycemia. She did not tell her physician that she had fibromyalgia, but her physician ended up asking her if she had fibromyalgia. When I asked P12 why she did not tell the physician initially, she replied, “It’s not that you’re embarrassed by it, but you’re like, what do they think? Do they treat you differently? And in that case, I was really trying to figure out what was wrong. I didn’t want somebody to say, ‘Oh, it’s fibromyalgia; don’t worry about it.’”

P12’s testimony hints at something that P16 states much more directly: “[The orthopedist’s] quote was: ‘People with fibromyalgia just get tendinitis for no reason’ That attitude of people with fibromyalgia, as though we were some weird class of people, just get tendinitis.” P16 said that she did not believe that

orthopedist and did not go see him again. Thus, fibromyalgia might be used as an explanation of some symptom that patients were experiencing, but this explanation was not only empty, it also left patients feeling that they had not been treated with respect.

Health Care Providers as Facilitators and Educators

Though there were examples of information gaps and information withholding, participants also related examples of the knowledge that health care providers shared or other types of growth that they facilitated. For example, P16 talked about how her provider shared research articles with her, which enabled her to learn more and engage in further information seeking. P19 said that her provider connected her with a hypnotherapy intervention that was extremely beneficial in terms of her health management. P26 remarked that her physician provided invaluable assistance in terms in her process of learning how to manage her health:

Ninety percent of what [the integrative physician] has told me I knew already, but the 10% that I didn’t know that he’s been able to help me learn is priceless. It’s kind of like losing that last five pounds when you’re on a diet. The first 20 are easy, but boy that last five are just hard, hard, hard. . . . It’s the hardest part, but it’s priceless. It’s priceless and I could never have figured it out on my own. (P26)

These sentiments were echoed by P14: “She’s just been a really wonderful source, and she educates me. I think doctors need to share.”

This educational process can involve lessons that may initially seem counterintuitive due to how illness and the treatment of illness are portrayed in society. For example, P12 recalled a conversation that she had with a nutritionist:

Nutritionist: Stop fighting. You’re putting all your energy into fighting. You don’t feel good, and you have some part of you that feels like you have to fight, but you’re wasting your energy fighting.

P12: But I’ve had to fight this. That’s what you’ve been told. . . . ‘Don’t give in. Fight it!’

Nutritionist: No! You need to take. . . . You need to take all your energy and put it towards something, towards growth!

This led to a fundamental change in her understanding of how to manage her health: “I think that was a really big turnaround, to think about: ‘This isn’t about battling something. Which, that’s always the word we use medically, always. You’re ‘battling’ cancer. You’re ‘battling’ heart disease. It was more like, ‘How do you make it part of you, but you’re still growing and thriving? It’s just a piece of you.’”

Many participants spoke of information that they had become aware of through mainstream media channels, including news articles, books, television, and others, that was produced by health care providers, physicians, and researchers. In some cases, it led to participants subsequently seeing those providers (P07 and P23), and P15 exchanged e-mails with the researcher, saying that she had changed her life. Though this type of information exchange is different than one-on-one patient–provider relationships, one might still think of it as an important type of connection, which results in both acquisition of concrete health knowledge and affirmation.

Collaborative Information Seeking and Problem Solving

Participants also reported examples of collaborative information seeking and sharing. One point at which this often occurred was concerning a person's diagnosis. Quite a few participants brought up the possibility of fibromyalgia to their doctor or another health care practitioner. Interestingly, there were also several that said that they thought they had fibromyalgia, but they did not tell their physicians because they knew that they were not supposed to self-diagnose.

One example of a collaborative process toward diagnosis was P13's experience. P13 first found out about fibromyalgia from his mother, who referred him to a website describing the condition. He thought it seemed plausible, and mentioned it to the physician, who looked into it in more depth. He and the physician engaged in a dialogue in which the physician told him that he fit the criteria for both chronic fatigue syndrome and fibromyalgia, but the physician ultimately diagnosed him with fibromyalgia because it encapsulated more of his symptoms.

Participants also engaged in collaborative information seeking and/or problem solving with their health care providers. P17 learned of an experimental medication for alopecia, and she mentioned it to her dermatologist. The dermatologist said that the medication had not been approved for women and that she was not comfortable prescribing it. P17 ended up trying something else after that visit, and the next time she went back to see this physician, the physician had done her own research and was then willing to prescribe it. But by then, P17 had thought it over and decided it was too risky for her.

This example illuminates several points. First, it is clear that both parties are engaged in the information seeking process and that their actions are dialogic: information seeking and communication on the part of one results in reflection and subsequent information seeking on the part of the other, and vice versa. The physician is open to receiving and processing information offered by the patient, and the patient also reflects upon the physician's opinion. The parties explore the information together and ultimately arrive at a decision, with the

ultimate responsibility for that decision resting with the patient.

Besides this type of iterative process of information seeking, participants also mentioned looking up information online with physicians in consultation, and one participant also said that she looked at her electronic health record with her physician. Another participant, P27, said of her physician that what she liked about her was that "she has a curious personality. . . . The first appointment, she's like, 'It sounds like what you're dealing with is really hard,' like, 'Let's try and figure out together what it is.'"

Identifying Health Care Providers

As stated earlier, participants in this study, as in past literature, experienced difficulties in finding health care providers that they could work with. Many participants' initial medical encounters were similar to those reported in previous literature, in which physicians exhibited skepticism regarding patients' symptoms. For example, one day P06 found her wrist extremely swollen and made an appointment with a rheumatologist. By the time of the appointment, the swelling had gone down, and the rheumatologist told her it was "all in [her] head" (P06). P13 said, "They [doctors] either thought I was being a hypochondriac or something or didn't believe me at all," and P23 said that doctors thought that she was seeking drugs. Thus, participants realized the importance of "vetting doctors":

Cross that one off! That's the wrong one! (P12)

If I can't find somebody that will work with me in a collaborative manner, then it's all over. I've just got to point where I won't put up with it. (P22)

They also identified characteristics that were important to them in their search for health care providers. Participants looked for open-mindedness, providing information, and leaving it up to participants to make their own decision:

When I'm vetting a doctor, I'm looking for someone who's open-minded, looking for somebody who's not going to just pooh-pooh acupuncture, or alternative practices, but also someone who's not just going to like, "Here. You need these 50 tests". . . . I really appreciate people who give me information, give me options, and then let me decide for myself. Because like, I want to understand; I don't want to be told. I also want to choose for myself. (P19)

The theme of physicians pushing pain medication was common and undesirable: "I'm very fanatic in some ways, about vetting doctors, because I don't want to be with someone who's just going to throw pills at me" (P19). Participants appreciated that providers allowed them to make their own decisions: "She relates to me.

She doesn't just try to push medicine on me. She'll suggest something and I'll say yea or nay, and she's good with whatever I decide. I never feel like she's rushing. I never feel like she has not got time for me" (P14).

P05 says, she has "had doctors that are very dismissive...who don't like it when you ask questions. I had one doctor who was just like, 'Take this medication,' and didn't want to talk about it. 'At least it's going to make you feel better; it'll take away the pain. So stop asking me all these questions.'" These encounters led her to realize that she needed to work with doctors who listened to her and were receptive to her questions.

Thus, in summary, participants developed various criteria for their providers, including taking the time and effort to listen to patients, being open-minded, sharing information and options, and not "being pushy."

Shared Responsibilities

As time passed, patients also developed a clearer understanding of what they expected of the patient-provider relationship. Participants were looking for "partnership medicine," not "here it is, go do it" (P12). Though patients had expectations of doctors, they also realized that they needed to do their part:

In a seven-minute appointment, they're going to listen to you for the first two minutes, and then they've already drawn their conclusion. That means as a patient, I need to go in clear and concise, not wandering... 'cause I've only got his attention for two minutes... I take paper in with me always. Sometimes I've written things down I want to ask ahead of time, and then I take notes. (P12)

Participants took steps to set an agenda for initial consultations. The participants spoke of "interviewing" doctors and counselors, of spending the first appointment just chatting with doctors rather than having a physical, to see if the relationship would work. P05 and P06 mentioned that they appreciated physicians who took time to go through their medical history with them on the first visit.

P12 believes that partnership medicine involves a relationship in which both parties have responsibility: "Doctors know some things, and you know some things. And you've got to have somebody who lets you put that together, 'cause you're the expert on your body, and they might be the expert on some treatments, but then you're the one that has to sort of be your own case coordinator and monitor your body" (P12). This was not a role that participants naturally took on, and it took time to learn: "It took me a long time to be the manager of my own health system. I expected doctors to kind of manage my life for me. It took me a long time to realize that, no, I'm in charge of this. The doctors that work for me are a team, and I manage that team" (P14). It is not always easy to put that team together. P15, for example, said:

Your doctor's just going to be looking at your illness. So you need to look at yourself until you can find a physician who practices integrative medicine or functional medicine... You can probably count those on both your hands in XYZ County, and they're not always covered by insurance. So you need to take things into your own hands. (P15)

Thus, one can see that, overall, participants came to view their health management as a team effort, involving multiple practitioners, but also an individual one.

A change in participants' expectations of their health care practitioners also led to smoother patterns of interaction:

I also figured out that doctors are not going to fix me. Initially it was just like, "Oh!" [Claps hands.] "Magic pill, magic pill, magic pill." But now I realized it's more like, they ease, they make it more comfortable for me to just do day-to-day, and so I don't have ridiculous expectations of what they can do for me, but also...and they're human. I think also because I've learned that, that it's a lot easier for me to interact with doctors and just ask them questions, and if they're the kind of people who are not open to that, then I need to switch. (P05)

Discussion

In this study, we explored the question of how fibromyalgia patients build successful relationships with physicians over time. We identified key factors that influenced the formation of these relationships: information interactions, finding providers, and realizing shared responsibilities. A successful patient-provider relationship includes multiple elements, in which patients and providers each contribute. On the one hand, patients learn to articulate their needs better over time and develop the ability to recognize health care providers that they can work with; they also recognize that they need to do their part. Practitioners, in turn, are open and listen to patients, give serious consideration to the information that patients bring to the consultation, and engage them in collaborative problem solving and dialogic information interactions. Gaps in knowledge, created by both patients and practitioners, impede productive clinical relationships.

The findings of this study have various implications for knowledge translation. As this study has shown, it can take time for patients and providers to build successful relationships, and there are ways that the process can be facilitated. First, patients gradually came to understand what they needed from providers and also learned what they could do to facilitate effective consultations. This process could perhaps be facilitated through the development of patient education materials that assist patients to identify characteristics that they consider important in selecting a provider, to help them communicate with providers, and to set realistic expectations. Our

study also illustrated the dialogic nature of information interactions and the diversity of information sources that may be involved, including the role that individuals around patients play in information interactions. We can provide tools for patients to organize the information that they gather from different information sources and communicate questions to providers. Usage of tools such as the notes mentioned by P12 can help to clarify stories and questions that patients may have and identify topics for providers to address in the interaction [44].

Providers, in turn, could receive more training in communicating with patients. For example, they might receive additional training in shared decision-making and in reducing high oral literacy demand in their communications, which has been shown to be detrimental to patient learning [45]. Previous research on providers' perspectives of the patient–provider relationships in chronic pain has also reported that providers experience strain and uncomfortable relationships with patients [46]. Helping providers to recognize their contributions can perhaps alleviate part of this burden. Additionally, they might receive materials that acquaint them with information that fibromyalgia patients may desire, including evidence-based information about complementary and integrative health (CIH) modalities. Table 2 presents an overview of the themes identified in patient–provider interactions and implications for practice.

This study also has implications in terms of implications for information provision. As has been observed in past literature, the increasing availability of health information on the Internet has empowered patients to seek information and play a more active role in their care. Though it has been argued that pre-encounter online information searching can have a negative effect on consultations, the literature has also shown that it can have a positive effect, empower patients to be more involved in the decision-making process, and increase patients' commitment to compliance [47]. In this study as well, we saw that patients both desired and played an active part in problem solving by doing research before consultations and bringing what they had learned into the consultation. Participants also engaged in dialogic information behaviors with practitioners, following up on leads provided by their health care providers. Though it may seem that these discussions might take more time, the statements made by participants such as P12 show that cognizance and consideration for the limited time that providers have and agenda setting could facilitate a concise and effective consultation. We are increasingly seeing innovations such as secure messaging and OpenNotes [48] that facilitate shared information sources between patient and provider. The development of features that reduce the burden of the provider to provide information sources and/or increase patient comprehension could be invaluable.

The results of this study are consistent with prior research on fibromyalgia patients' communication

preferences, which has reported that many patients prefer an open style of communication [49] and prior research on trust in rheumatic conditions [50], in which physicians' sensitivity, informativeness, and patient-centered behavior have been shown to predict trust. Additionally, this study showed that successful long-term relationships that patients shared with providers often involved mutual understanding and forbearance. Participants in this study did not always get what they wanted. In particular, they recognized that providers were “human” and that there were structural constraints due to the insurance plans they belonged to and guidelines providers needed to adhere to because of the health care systems they operated in. Mutual understanding is important because better physician–patient collaboration has been reported to be associated with better patient adherence [51], relationship continuity is foundational for experiencing informational and management continuity [52], and continuity of care has been shown to be associated with patient satisfaction [53].

However, what this study highlights is the need for both patient and provider to realize that the other is not a static entity. As this study has shown, participants learn a great deal over time, and this evolution can involve a clearer self-articulation of what they need from providers. They are not looking for providers to be “perfect,” but “partners.” Additionally, they may also shift from expecting physicians to “solve their problems” to an expectation of a shared responsibility. Understanding on the part of both parties can facilitate more sustained, interactive exchanges in which the patient and provider work together to solve problems over time.

Extant literature has argued that educational interventions for pain can lead to improvements in pain management [54]. An explanation that resonates with a patient can both empower them and enable them to move forward [55]. Conversely, explanations and diagnostic labels can not only lack meaning [11], but also offend patients [56]. Thus, one question that might arise about this sample would be how providers' explanations of pain affected participants' behavior. Though we did not systematically investigate this question, we considered this question in light of the experiences presented in this article. First, we have related examples in which participants were frustrated when providers offered up fibromyalgia as the cause for what they were experiencing, were unwilling to explore or discuss alternative explanations, and focused on prescribing pain medications. This not only left participants feeling that they still wanted answers, but also led to increased information seeking, withholding information from providers, and provider switching. Conversely, there were also situations in which patients reported reacting positively to transparency from providers and the knowledge they shared, which occasionally also led to episodes of collaborative information seeking. Lastly, changes in patients' perspectives

on health and well-being occasionally also led to better communication with providers. These experiences highlight that the building of patient–provider relationships is a gradual and dialogic process in which open communication, information sharing and collaboration, and adopting a long-term view can be of tremendous benefit.

This study has various limitations. First, this study involved a limited sample of participants who mostly resided in the United States, and thus the experiences related by participants are likely to reflect elements of clinical care in the United States. For example, most but not all participants who developed symptoms more recently had shorter diagnosis times and experienced more understanding from their physicians. We suspect that these changes may reflect the change in diagnostic criteria for fibromyalgia in 2011 [57]. In addition, the participants in this study were primarily female and white. The interactions that fibromyalgia patients of other backgrounds may have with their providers may be different; this is an important area for future research.

This study also involves the retrospective recall of patient experience. Participants in this study shared their experiences of building relationships with providers perhaps years or decades after they began dealing with their conditions. The clarity of participants' memories and their salience might change over time, and the accuracy of their memories could also be an issue. In addition, this study is focused on patients' perspectives, and providers may have had different perspectives of their interactions with these patients. Although interviewing the providers also would have been valuable, this was outside the scope of the current study.

Last, in this study, participants are depicted as having switched and gradually developed cognizance of the ability to choose providers along the course of their illness journey. The question might arise of whether all patients have the opportunity to choose. Many barriers to equal opportunities for choice exist. For example, patients may be limited to selecting an in-network provider or be limited in terms of the money, time, or likely both that they are able to spend on health care. Because our sample was highly educated, they may have perceived more options than the general population, and more research is needed to determine whether patients with fewer options might build relationships with health care providers.

Conclusions

In this article, we considered two important elements of patient–provider interactions in the context of fibromyalgia: the role of information in patient–provider communication and the development of patient–provider relationships. Patients in this study had interactions in which they were able to successfully build long-term relationships with their health care providers. We explored some of the key factors affecting these relationships, including information gaps, the provider as an educator

and facilitator, collaborative information seeking and problem solving, identifying health care providers, and engaging in partnership medicine. Bridging information gaps, collaborative information seeking and problem solving, and partnership medicine can be invaluable in forging successful clinical relationships.

Patients and providers both need to contribute in order for clinical relationships to be successful. Training and education can be helpful. For patients, providing information about selecting and working with providers and how to make the most of clinical consultations can improve productivity. For providers, learning more about patients' expectations can help them to provide better care.

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Appendix

Box A1. Interview Guide

Consent form and pre-interview questionnaires

Now let's proceed with some questions about your health history.

1. Can you tell me when your health issues first began?
2. (probe further) Can you tell me more about that?
3. How did you feel at the time?
4. What sources did you go to for help? (This can refer to medical help, social support, or information.)
5. How were those initial experiences?

Timeline activity (30 minutes)

(Give sketchpad.)

I'd like to ask you to think back to when you started experiencing health issues, or further if you think it's relevant. Think about the path, the journey you took, to get to today.

I'd like to ask you to draw something to represent what happened. You can use different colors to represent different aspects of your experience.

(Take out or point to colored pencils and highlighters.)

If you need more paper, we can attach an extra sheet.

Please talk aloud as you are drawing the timelines. You can just talk to me about what you are drawing, why you are drawing it, anything that occurs to you. The purpose of me asking you to talk aloud is to help me understand what matters to you, and also to understand your memories as you do.

Prompt the participant if he or she falls silent.

Some possible probes include:

Could you tell me about what happened then?

Could you tell me about what you're drawing now?

Could you tell me about that change?

Suggest that the participant add the following to the timeline:

Emotions

Turning points

Gradual changes (e.g., periods of frustration, periods when you felt that things were going well)

Important events (“What would you say is an important event?”)

Ask the participant:

1. What do you think are the five most important events that have occurred on your illness journey?
2. Thinking back to your illness journey, at what points do you think information came into play? Can you note these points on the timeline?
3. (probe) In what ways did information come into play?
4. Throughout your illness journey, what information was most important to you?
5. Did you look for information? (If yes, why?)
6. Did you receive information from practitioners or people around you?
7. How did you feel at these times? (Frustrated? Hopeful?)
8. Do you remember anything that you learned, or any information you received, that changed the way you viewed your illness, your health, or your life?
9. Do you remember anything that you learned, or any information you received, that changed the way you do things or manage your illness?
10. From what sources did you receive information? Have these changed throughout the time that you have had your condition(s)?
(After the participant is done, ask them some questions to try to clarify points that may be unclear, if any, on the timeline.)

Follow-up questions (30 minutes)

11. Do you feel that you have generally received the information you need to know how to deal with your condition?
12. Today, do you feel that you still need information about your condition, and if you do, how do you go about finding what you need? (Make sure that they touch upon the sources that they use, how they conceptualize the search, and their search strategy.)
 - a. What sources did you use?
 - b. How do you go about looking for information?
13. Now, can you tell me about how you manage your condition today?
What do you see as your priorities?

14. Has your management strategy changed over time?
15. Do you see this changing in the future, and if so, how?
16. How do you feel about your health now?
17. What do you think that health and wellness mean?
Has this changed for you over time?
18. Do you feel that those around you are supportive of you?
19. Where do you personally go for support?
20. Is there anything else you want to tell me about your illness journey?

This is all I have for today. Thank you so much. Before our next interview, I will collect the content that you have authored online, and then we can review it together. Thanks again, and I’m looking forward to our next meeting!

Table A2. Participants’ Ages and Health Histories

	Age, y	Onset Year	Duration	FIQR Score
P05	27	2008	6	45
P06	49	1998	16	48
P07	79	1956	58	41
P08	52	2000	14	33
P09	26	2006	8	51
P10	32	1996	18	24
P11	31	1999	15	51
P12	65	1985	29	14
P13	21	2012	2	54
P14	54	2008	6	53
P15	59	2009	5	61
P16	66	1969	45	39
P17	62	1993	21	50
P18	60	1989	25	37
P19	37	1999	15	40
P20	44	2004	10	80
P21	56	2004	10	27
P22	60	2008	6	63
P23	61	1985	29	64
P24	27	2012	2	58
P25	51	1983	31	50
P26	57	1980	34	52
P27	31	2013	1	51

FIQR = Revised Fibromyalgia Impact Questionnaire.