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Coping with a dead end by relying on your own compass:

A qualitative study on illness and treatment models in the context of fibromyalgia

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Abstract

Fibromyalgia lacks a coherent illness and treatment model, which includes a set of conceptual ideas shaping individuals’ perceptions and understandings of pain, its causing and maintaining factors, and management strategies. Developing personalized illness models that can guide treatment plans and alleviate feelings of uncertainty, is of crucial importance. This study investigates how individuals with fibromyalgia develop a personal illness and treatment model while navigating the current healthcare system and explore their experiences during this process. Semi-structured interviews were conducted with 15 cis women with fibromyalgia, which were analyzed using reflexive thematic analysis. The analysis produced two themes, each including two subthemes. The first theme encompassed the difficulty of developing a comprehensive illness model due to the biomedical perspective of the healthcare system; the second theme described the importance of participants (re)gaining ownership and agency over their pain management, by constructing their own illness and treatment model. Most women in this study got stuck in the biomedical healthcare web not being provided with a clear illness and treatment model. Consequently, most women gained ownership of this process by developing their personal illness and treatment model (self-empowerment). Conversely, a few women felt powerless and paralyzed. This study underscores the importance of promoting patient empowerment in chronic pain management. Agency is undervalued in the treatment of fibromyalgia and warrants more thorough examination. Increasing knowledge about agency could enhance treatment effectiveness.

Key words: fibromyalgia, illness models, treatment model, agency

Introduction

Individuals with primary chronic pain (CP) conditions, such as fibromyalgia, typically experience persistent or recurrent pain (at least three months) without a clear underlying physiopathology. Both individuals with fibromyalgia and their healthcare providers often struggle to make sense of these symptoms (Wuytack & Miller, 2011). Unlike other conditions such as rheumatoid arthritis, fibromyalgia lacks a coherent illness and treatment model, which includes a set of conceptual ideas shaping individuals' perceptions and understandings of pain, its causing and maintaining factors, and potential management strategies (Quintner et al., 2008).

Qualitative research has shown that the uncertainty surrounding the aetiology of fibromyalgia leads to frustration and anxiety, both during the diagnostic process and thereafter (Boulton, 2019; Mengshoel et al., 2018). This uncertainty leaves patients unsure about their future (Neville et al., 2019), emphasizing the importance of developing personalized illness models that can guide treatment plans and, alleviate feelings of uncertainty, distress and self-doubt (Leventhal 2016; Hagger 2022, Barker, 2002).

In doing so, a biopsychosocial illness and treatment model approach to illness and treatment models is increasingly recognized as essential for understanding and managing CP conditions (Gatchel et al., 2007), including fibromyalgia (Turk & Adams, 2016). This approach incorporates biological/medical, psychological, and social factors in the treatment of pain (Gatchel et al., 2007). However, the lack of medical consensus on the aetiology and treatment of fibromyalgia poses significant challenges. To date, research has yet to explore how individuals with fibromyalgia navigate the dynamic process of developing personal illness and treatment models, and whether these models reflect a biopsychosocial perspective.

Importantly, the development of personal illness and treatment models does not occur in a social vacuum, but is embedded in the complex context of the healthcare system and one-on-one interactions with providers. Mescouto and colleagues (Mescouto et al., 2022) argue that research and healthcare often conflate the biomedical and the biopsychosocial model, thereby neglecting the complexity and interplay of psychological and social dimensions, which are crucial for understanding the causation and persistence of conditions like fibromyalgia (Paschali et al., 2021; Wolfe et al., 1998).

Moreover, a shared illness and treatment model between individuals with fibromyalgia and their healthcare providers is essential, as it facilitates a mutual understanding of pain, its causes, and management strategies (A. Byrne et al., 2023; Chen & Swaminathan, 2020). However, fibromyalgia's misalignment with the biomedical model (absence of clear aetiology) in Western healthcare has historically complicated the development of such shared models (Dahm et al., 2023). This misalignment has contributed to strained patient-provider communication and weaker working alliances, as noted in individuals with chronic pain in general (DeRuddere et al., 2013; Stinesen et al., 2019). Furthermore, many individuals with fibromyalgia report experiences of invalidation during healthcare encounters (e.g. (Armentor, 2017; Ghavidel-Parsa et al., 2015; Hasselroth et al., 2021; Nishikawara et al., 2023), often due to healthcare professionals' limited knowledge about the condition and its treatment options (Billing et al., 2007; Hayes et al., 2010; Kumbhare et al., 2018). Positive interactions, however, can empower patients to adopt adaptive coping strategies, such as accepting their condition and seeking education (Antunes et al., 2021; Hamama & Itzhaki, 2023; Råheim & Håland, 2006).In light of these challenges, the current study aims to explore these experiences in the context of developing personal illness and treatment models.

The current study addresses this gap by focusing on the lived experiences of women with fibromyalgia and considering the social contexts (healthcare system and encounters) in which these experiences unfold. Given that fibromyalgia predominantly affects women and it is often perceived as a "women's condition", this study focuses specifically on women to better understand the unique experiences and challenges they face. The research question guiding this study is: How do women with fibromyalgia develop personal illness and treatment models while navigating the current healthcare system and how do they experience this process?

Method

Participants

Participants were recruited from patient organizations that had previously shown a willingness to participate in future studies at our institution. They were contacted by phone by a member of the research team and provided with an information letter about the study, after which they could confirm their interest in participating. Inclusion criteria were (1) being at least 18 years old, (2) self-identifying as woman, (3) having a diagnosis of fibromyalgia and (4) speaking Dutch as their native or first language. Twenty-two people were contacted to take part in the study. Seven individuals refused to take part, either due to a preference for online questionnaire studies or personal circumstances. Participants did not receive a compensation.

The final sample comprised of 15 cisgender women diagnosed with fibromyalgia, ranging in age from 24 to 68 years. The determination of the sample size was guided by data saturation. All participants reported comorbidities such as arthrosis, chronic fatigue syndrome, pelvic instability, hernia, spasmophilia.

Data collection procedures

INSERT TABLE 1 ABOUT HERE

A semi-structured topic guide was developed and piloted (Kallio et al., 2016), containing opening questions, key questions and closing questions (see Table 1). Additional prompts were available to explore topics more in detail. The interviews commenced with an ice-breaker question “Can you tell something more about your pain complaints?”. Using this open question the interviewer aimed at fostering a trusting relationship with the participants. Participants had ample opportunity to provide detailed elaboration. Most participants started talking about their illness trajectory and in doing so, highlighted topics directly relevant to our research question. Prompts that could be given contained questions about onset, duration, location, and evolution of their pain complaints. Afterwards, more targeted questions were asked, exploring their ideas about the cause of their pain, their perceptions of effective treatments, and their interactions with healthcare providers.

Interviews took place between December 2021 and September 2022. Some participants were visited in their homes for the interviews, while the majority were conducted online via videocall. Participants were asked beforehand to arrange a quiet room for themselves (if possible). This online format was chosen either due to COVID-19 restrictions that were enforced at that time or at the participants' request for social distancing. The first author conducted all interviews. Prior to the start of the interview, she gave information about the study objectives and participants provided written informed consent. The interviewer explained that she is a PhD candidate working on social factors related to chronic pain. Interviews were audio-recorded and transcribed verbatim. All personal and identifiable information (e.g. names of doctors, cities, etc.) was removed during the transcription phase. Interviews lasted between 1-2h. The interviewer encouraged participants to answer freely, allowing them to elaborate on specific topics they deemed relevant and skip over questions that felt too personal. Additional questions were asked by the researcher if necessary. Upon completion of the interview, participants were asked about their sociodemographic (i.e., sex, gender, age, education, occupation, diagnoses, pain duration) and pain characteristics (using the Graded Chronic Pain Scale – Revised, Von Korff et al, 2019). Ethical approval was provided by the Faculty of XXX (XXX).

Data analyses procedures

Interview transcripts were subjected to Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2006, 2021a). This approach was selected as it aligns with the research question, which aims to explore both the lived experiences and sense-making processes of participants, while also contextualizing these experiences within the broader dynamics of the patient-provider relationship and clinical setting (Braun & Clarke, 2021a). RTA positions the researcher as an active subject making sense of the data (Braun & Clarke, 2021a), emphasizing a social **constructionist** perspective (Gergen, 1999) rather than a positivist perspective (focused on hypothesis confirmation or rejection). This methodological choice prioritizes the subjective experiences and sense-making of participants within the specific context under investigation. (D. Byrne, 2022).

This approach contained six analytical phases (Braun & Clarke, 2021b; D. Byrne, 2022). The first phase began after the completion of the initial twelve interviews. In this phase, two researchers (XXX) familiarized themselves with the data through active and repeated reading of the transcripts (each read half) and providing initial notes in the left-hand margin. In a second phase, both researchers created a list of initial notes/codes in the right-hand margin of the transcript through an ongoing process of open and organic interpretative engagement with the data. An initial note/code represents the most basic segment or element of the raw data that can be assessed in a meaningful way regarding the phenomenon of interest. Notes/codes were not considered permanent, but could evolve and change throughout this process, reflecting the researchers' deepening immersion in the data. In the third phase, XXX combined the initial notes/codes into potential themes reflecting a shared implicit meaning underpinned by a central organizing concept. Each theme also contained extracts and notes drawn from the text that reflected this theme. Following the addition of each transcript to the thematic structure by XXX, a preliminary review was conducted by XXX to ensure consistency and accuracy. As such, an initial thematic map was generated, outlining the identified themes and sub-themes. Following this, we conducted three additional interviews to ensure that the collected data contained sufficient relevant information to address our research question. In a fourth phase, the final structure of themes and sub-themes underwent a comprehensive review by XXX, XXX, and two additional members of the research team (XXX and XXX). During this phase, we revisited specific interviews and made minor adjustments to the thematic structure. In a fifth phase, each theme and subtheme was labeled, defined, and supplemented with a detailed narrative as well as accompanying quotes drawn from the text. After reviewing this, some quotes were reassigned to multiple themes or moved to a more appropriate one. Finally, in the last step, a written report was produced.

Quality appraisal

Frequent and systematic feedback was provided by XXX and XXX and the rest of the research team to build insight, enhance collective understanding of the data, ensure conceptual coherence and prevent thinness and fragmentation in the analytical process. Any conclusions and decisions reached during this process were documented as notes in the analytical protocol. Discussion of themes was accompanied by quotes directly extracted from the raw data, as well as a detailed elaboration of how their meaning was interpreted by the researchers. Rich and elaborate descriptions of constructed themes were provided. Furthermore, Braun and Clarke's (Braun & Clarke, 2021a) evaluation tool for thematic analysis was thoroughly reviewed to ensure adherence to the best practices.

Lastly, the above-described analytical steps were executed whilst maintaining a stance of rigorous reflexivity. As such, the researchers thoroughly considered their own positionality in relation to the research objectives. XXX, XXX, and XXX are clinical psychologists. XXX is a social psychologist and XXX is a sociologist. XXX is a doctoral student and has regular contact with individuals experiencing chronic pain in the context of research, but also in clinical practice. Her PhD focuses on stigma and social networks in the context of chronic pain. XXX is a postdoctoral researcher with expertise in qualitative research about injustice appraisals. She is also doing clinical work and has expertise in working with individuals with CP. XXX, professor, brings expertise in qualitative studies focusing on individuals with chronic pain/illness. XXX is a full professor in sociology, specialized in (population) mental health and illness. XXX is full professor of clinical health psychology and works in a clinical practice and has also expertise in treating with individuals coping with CP. XXX, XXX, and XXX are Belgian white cisgender women. XXX is a Portuguese white cisgender woman. XXX is a Belgian white cisgender man. As researchers in the chronic pain field, we have prior knowledge of how pain care is delivered in Belgium and ideas on potential improvements. Additionally, with our psychological background, we tend to focus more on psychosocial aspects, potentially moving away from a purely biomedical approach. This naturally sparked our interest in the topic. As therapists, our initial tendency is to empathize with patients, which may sometimes influence us to focus more on the role of the healthcare system in the challenges they face. However, since we also collaborate with healthcare providers in pain clinics, we incorporate insights from their perspective into our research as well.

Results

Table 2 summarizes the sociodemographic and clinical characteristics. All women were given a fictious alias.

INSERT TABLE 2 ABOUT HERE

Reflexive thematic analysis of the data generated two main themes (each comprising two subthemes) representing how Belgian women living with fibromyalgia made sense of, thought about and experienced their pain, treatment, and interactions with healthcare providers. The first main theme elucidates the struggle of constructing a workable illness model within a predominantly biomedically oriented healthcare system. The second main theme describes how participants address this challenge by (re)gaining agency and actively participating in the development of their own illness and treatment model. Anonymized quotations are provided that demonstrate how our analysis is firmly grounded in the interview data.

Theme 1: The lack of a clear illness model in a biomedically oriented healthcare system

Subtheme 1.1: Struggle to find a diagnosis

Many of the participants emphasized the challenges they faced during their diagnostic trajectory. At the onset of pain and other complaints, participants tried to make sense of their symptoms and searched for a diagnosis. Indeed, in a biomedically oriented healthcare system – such as that in Belgium – a diagnosis usually identifies a clear pathology and prescribes a clear course of medical action. However, because of the nature of the complaints (e.g., pain, sleeping problems, cognitive problems) and the lack of an immediate or clear medical explanation, navigating the healthcare system - finding out who to consult with and where - was a substantial challenge. Additionally, participants articulated that a variety of their complaints did not align with the biomedical system, which typically focuses on and operates around clear symptom patterns associated with specific diagnoses. Moreover, due the emphasis on biomedical diagnoses, we noted a power imbalance between themselves and healthcare providers with the latter having more authority by virtue of being the ones to assign diagnoses to the participants. These challenges contributed to a long journey in finding a diagnosis, as reflected in the following quotes.

"I: how did you get the diagnosis? How did it go? P: by searching really hard, uhm which is also frustrating. Because the complaints started slowly. First, you have pain in that place, then you have it

somewhere else and then you think "it is stress and bla bla bla". And then you notice "there is really something wrong" and then you start searching." (Daisy, T8) and *"And then the struggle began, what is it, what do you have, where do you go, who can help you, yes pff."* (Kim, T7). Here, Daisy emphasized that getting a diagnosis was a difficult and long process. However, Kim pointed out that even when a diagnosis is obtained, the struggle continues, whereby participants need to figure out where to find the right professionals to appeal for help.

Participants described that the nature of the complaints (e.g., widespread pain, fatigue, cognitive problems) often hampered an efficient diagnostic process, as their onset was often gradual and the condition involved physical complaints manifesting in different body parts, as described by Daisy: *"They (healthcare providers) do not see it in a holistic way. They regard the different complaints separately. They examine the heart, the liver and so on. That is the problem, fibromyalgia entails so many different complaints. And you have to be able to look beyond that to see the cohesion."* (Daisy, T8)

Moreover, participants' narratives showed that getting a diagnosis of fibromyalgia fails to provide the expected biomedical trajectory. Instead, participants echoed that it is considered a diagnosis of exclusion, which can be stigmatizing in itself. Participants contended that the healthcare system exhibits a lack of knowledge about certain conditions or symptom patterns resulting in diagnoses of exclusion. They noticed that healthcare professionals only considered fibromyalgia after ruling out all other possible conditions. Fibromyalgia is perceived as a catch-all term, meaning that it encompassing various different complaint patterns that cannot be classified elsewhere. Kim (as quoted below) refers to the diagnosis as a "dustbin", emphasizing its status a residual category that does not neatly fit into conventional classifications. This sentiment reflects a profound sense of frustration or disappointment. As a result, participants felt marginalized by the system, which seemed ill-equipped to address their needs.

"Uhm, of course, when she diagnosed me, she did other examinations in the hospital, uhm. To make sure that there is no other cause. That is what they do with fibromyalgia, excluding all the rest. And then it is the dustbin". (Kim, T7)

"It is still a diagnosis of exclusion. Or it was like that in my time: "if we don't know, then you have fibro". But fibromyalgia also includes specific symptoms." (Daisy, T8)

However, when eventually obtaining a diagnosis (of fibromyalgia), participants agreed it was of no great help: *"Yes, but fibromyalgia is such a term. They use it for lots of conditions and then you're stranded."* (Lily, T10). In the following quotation, Mia described having mixed feelings upon receiving her diagnosis: *"Euh, gosh, it was a relief, but thinking further… yes, does it help you? Actually not, because it only starts then."* (Mia, T4)

The lack of sufficient knowledge to provide a clear underlying pathophysiology inevitably entails a lack of explanation for the pain condition and therefore less understanding for the patient. Participants attempted to identify the factors contributing to their complaints, yet a pervasive sense of uncertainty prevailed. They felt powerless and not understood. In the following quote, Alice emphasized that she did not understand how the condition developed; it demonstrates the feeling of powerlessness: *"I don't understand how such a condition is even possible"* (Alice, T9)

In summary, the results suggest that the diagnostic process is also highly challenging in the current healthcare system. Obtaining an accurate diagnosis poses difficulties, and coping following the diagnosis proves equally arduous. These challenges originate from the diagnosis lacking a specific illness model, such as involving demonstrable causes.

Subtheme 1.2: Struggle to identify appropriate and effective treatment

Throughout the participants' narratives we interpreted that due to the absence of a consensus on the illness model, there is a corresponding absence of clear treatment guidelines. Without a definitive understanding of the underlying cause of the pain condition, the diagnosis of fibromyalgia fails to provide straightforward treatment guidelines or a clear-cut approach to pain management. Participants noted a perceived lack of knowledge among physicians regarding the condition, as illustrated by the following quote: *"The general practitioners, but yes, he does not know a lot about fibro…"* (Julia, T6).

Participants expressed feeling abandoned by the healthcare system in the process of finding (biomedical, physical, and psychological) treatment options to help manage their pain. *"Yes, because they (doctors) also don't know. If they have to admit that it is fibromyalgia, yes, they still encounter a dead end. And then they believe in it or they don't. Yes (sighs), a solution will not be for tomorrow."* (Kim, T7). *"It's not an option, looking at it from the traditional medical world. If nothing can be found, everything stops."* (Anna, T3). Kim and Anna described that the road ends after receiving the diagnosis as there are no guidelines and Kim even calls this a "dead end". The emotional weight conveyed in these quotes is palpable. Further, one participant vividly described getting stuck in the healthcare web, uncertain of the eventual outcome: *"Ehm, you always get caught in a web, so to speak, and you don't know where you'll end up."* (Sarah, T2). Sarah's portrayal of the challenge uses powerful language, painting a very strong emotional picture of being trapped in a complex situation, with nowhere to go.

Some participants pointed out that providers focused on specific body parts, inadvertently overlooking the body as a holistic entity. They emphasized the need for a holistic perspective on fibromyalgia in treatment. A few participants said that specialized care focusing on individual and isolated parts of the body was not appropriate as fibromyalgia is a widespread condition affecting different functionalities of body and mind. Some of them turned to alternative medicine, because of its stronger emphasis on viewing the body as a holistic entity: *"It is my experience that it is easier to be open in alternative medicine. Because classic medicine focuses on blood results and imaging material and if they don't find anything then it is psychological. That is my negative experience."* (Anna, T3). This woman described that she searched someone with the same attitude as her, namely being open and thinking holistically.

Because of the lack of biopsychosocial treatment guidelines, the biomedical healthcare system still focuses predominantly on medication, which is illustrated in the following two quotes.

"(participant quoted doctor) And uhm, actually I cannot help you. Because yes, you have a diagnosis. I cannot do more than give you morphine patches." (Alice, T9) and *"Further, these are very traditional doctors, who focus on medication. But yes, that is contradictory because there is no medication for fibromyalgia. Only palliatives."* (Kim, T7). This was a problem in the case of fibromyalgia as there is no effective medication. Participants may experience some pain relief thanks to painkillers, but this treatment focused more on symptom reduction rather than actually curing the condition: *"Last week I went to the general practitioner and asked if there is something new for fibromyalgia, but she could not help me despite saying that there are painkillers and antidepressants, but it does not help."* (Olivia, T13)

Related to this, antidepressants were frequently prescribed, which was perceived as stigmatizing. This perception likely stems from the interpretation of this action. Specifically, most participants perceived the prescription of antidepressants as if doctors were implying that their pain had a psychological origin, which they interpreted as less authentic and real, and not to be taken too seriously. This is illustrated in the next quote: *"It is a combination of painkillers and antidepressants, and with that I do have a problem. I don't think that I am depressed. I am in any event skeptical, uhm, to give that as medication on a regular basis. I prefer to not do that."* (Kim, T7).

Some participants, despite their personal frustration, also sympathized with physicians, sensing a shared sense of powerlessness on their behalf, which is described in the following quote: *"So yes, he said yes, learn to live with it… learn to live with that, but those doctors stand with their backs against the wall and do not know what to do." (T2)*

However, we found that many healthcare providers failed to acknowledge this sense of powerlessness during consultations and instead sought to maintain their authority (and power). On several occasions, it was noted that if doctors were unable to cure the condition, they would terminate the healthcare relationship with the patient. The disruption of these healthcare relationships may increase the feelings powerlessness for both participants and professionals. As Julia expressed: *"I think a year ago that it was, he said "I cannot do anything more for you". After all those years. He said "I* *know your condition and it will not get better". And he said that it had no purpose to keep consulting him. But that was… I thought "such a confidant that disappears suddenly".* (Julia, T6). This dynamic contributes to a perceived lack of validation for the patient, as the physician behaves as if no further treatment is necessary.

These struggles may have ultimately resulted in a lack of trust in the healthcare system as a whole. Indeed, participants sought answers and clear treatment plans from the healthcare system, yet this expectation was not fulfilled as described by Anna: *"I am disappointed in healthcare. I have lost my faith in it."* (Anna, T3)

Overall, the absence of a clear illness model contributes to a lack of treatment model. Participants were in search of treatment guidelines, but encountered barriers within the healthcare system, such as a lack of knowledge and collaboration between healthcare disciplines.

Theme 2: (Re)gaining ownership/agency (self-empowerment) in developing their own illness and treatment model.

Due to the limited or inadequate response from the healthcare system in providing effective treatment for their pain or clear treatment guidelines, many participants took matters into their own hands in search for answers. In doing so, participants **tried to regain control** over their lives and a **sense of empowerment**. They experienced this as a transformative process of coping with the challenges they encountered. For instance, a few participants proactively suggested fibromyalgia as a potential diagnosis during consultations with healthcare specialists, as exemplified by Kate: *"And eventually it was my mother-in-law who said that my complaints resemble fibro and she is also ill and uhm because she said that, I approached the doctor with that information. In that way, they found out it was fibromyalgia."* (Kate, T11)

In response to the medical world's lack of answers, some participants constructed their own illness and treatment model for their pain experience, primarily through **self-education**. Almost all participants read books about the condition, went to talks, approached fellow patients, and so on. We found that this process allowed them to gain a sense of agency over their health over time as illustrated in the following quote: *"I had to figure everything out myself. I had to read and study. And I am grateful that I have cognitive capacities."* (Daisy, T8)

Conversely, a few participants expressed feelings of complete powerlessness, described as a sense of lacking control or agency over their circumstances. They articulated these sentiments in an almost fatalistic way: *"Not able to do what you want, your body decides what you do and what you don't do".* (Sarah, T2) and *"It influences everything, everything. And it controls your body. You are not the boss anymore".* (Sarah, T2). (Olivia, T13). The following participant emphasized that she just followed what doctors said: *"I am… yes not someone who stands up for oneself, thus I just followed."*. Olivia avoided discussing issues with doctors and shied away from potential conflict, resulting in suboptimal pain management. It is notable that both Sarah and Olivia are women who did not receive higher education. Additionally, considering that only four years have passed since receiving the diagnosis, it is possible that some participants are still in the early stages of the acceptance process, which may contribute to feelings of powerlessness.

Some participants stopped seeking care from healthcare providers due to repeated and ongoing disappointments, as described by Kim: *"I: And do you still go to physiotherapists or osteopaths? P: no more. I: nothing at all, no. P: No. I: So actually now there are no healthcare providers for fibromyalgia? P: No, nobody, nothing."* (Kim, T7)

Subtheme 2.1: Developing a biopsychosocial oriented illness model.

Interestingly, overtime, participants constructed a more **biopsychosocial perspective** on illness and treatment. In addition to acknowledging biomedical factors contributing to pain, there was a notable emphasis on the role of psychosocial factors in either causing or triggering the pain condition. First, participants frequently communicated experiences of **trauma and stressful psychosocial events** from their past, as illustrated in the two following quotes:

"I have always been on my own. I have not had a good home/family situation. My mother was always uhm, depressed. Uhm, pff, narcissistic mother also." (Amy, T1)

"I divorced for the second time in 2006 and that was basically the trigger that caused my problems, yes I have probably recovered from this by now, but that took years, years, years before I was… That was completely unexpected, and I ended up badly, really bad." (Kim, T7)

Second, most participants acknowledged having exceeded their own limits, both physically and mentally, over a prolonged period or in an extreme way, often by prioritizing others and neglecting their own needs. For instance, Alice expressed: *"I had to take care of my child. I have experienced times that my child, my child was never short, but I survived on a Mars (chocolate bar) and a coke. I barely weighed 45 kilograms."* (Alice, T9). Additionally, she reflected on her upbringing: *"Yes, I have always worked hard and at home we were raised like that. I have two hard working parents and they mainly emphasized that it was important to have awe, awe. Awe for your superiors, for your boss. Yes that was maybe a bit too much. A bit. In such a way that you always nod yes when your boss asks something."* (Alice, T9). Alice explained that she had no financial resources to live a proper life and that she was taught to work hard and defer to authority figures. In this way, she exploited herself in various ways over the years. Despite warnings from doctors, participants continued pushing their boundaries until reaching a "crash" point, as described by Marie:*" I felt that something was wrong. Then I came back to the general practitioner months later. She said the problem was the same. You have to rest, you really must rest. Again prescribed to stay home and I kept working. Until a day that it was so bad…"* (Marie, T5). Participants emphasized that both past and current social contexts play a role in the causation of their pain.

However, despite recognizing the role of psychosocial factors in their condition, participants continued to seek a biomedical explanation for their condition, aligning with the predominant focus on biomedical factors in healthcare. Conforming to the biomedical-oriented healthcare system was often more convenient than not conforming to it. As Lily expressed: *"I hope, in some way, that fibromyalgia will be visible on a brain scan, because then you can show like: 'look, there is a genuine issue and it is* *situated between the ears, distinct from purely mental factors' "* (Lily, T10). This participant expressed a hope for future concrete evidence of fibromyalgia within the brain, highlighting the pressure from the healthcare system to prioritize a biomedical explanation.

In summary, over the years, participants learned about possible factors contributing to the development of their conditions. Most of them acknowledged both biomedical and psychosocial factors in the causation process.

Subtheme 2.2: Transitioning from a treatment model to a coping model.

In the absence of a clear treatment trajectory for their pain condition, participants embarked on constructing their own treatment model. However, for many participants, this process entailed gradually assembling puzzle pieces; exploring various treatment options (conventional or unconventional) that could help manage or cope with their pain. This model involved actively **seeking out and trying different treatment modalities** within and beyond the traditional realm of medicine. Participants emphasized the importance of feeling proactive and taking action, suggesting that agency played a crucial role in fostering a sense of acceptance and positivity, as described in the following quotes:

"I think that I have accepted it. I am undertaking lots of things for it. I know what I have to do. I am making the best of it. So, for me I have accepted it at a certain level." (Grace, T15)

"and it is not that this man can cure me directly, but we learn and after the consultation we can talk about it: what do you think? Maybe that is something? In that way we are positively undertaking things. That is basically it, don't give up and don' t do it fanatically, but always willing to work on in a positive way." (Anna, T3)

Additionally, participants emphasized the importance of maintaining a **positive** outlook and focusing on things that were still possible as coping strategies: *"So you learn to really enjoy things that you can still do".* (Anna, T3). Also, engaging in physical exercise was identified as a coping strategy: *"But I am convinced that movement remains also very important as a fibro patient."* (Lily, T10).

Moreover, consistent physiotherapy was highlighted as crucial for nearly all participants in managing their condition.

Furthermore, it became apparent that most of these participants had a (romantic) partner accompanying them on their journey, engaging in communal or dyadic coping. Some participants referred to themselves and their partners as a unit, using terms like "we" when discussing their approach to managing the situation, such as "we are searching for other options". This suggests that having a stable social network was important for developing and maintaining a sense of agency and control. Additionally, participants also emphasized the importance of psychological support alongside biomedical treatments, as articulated by Daisy: *"At the time of the diagnosis, I also started therapy for the mental part."* (Daisy, T8).

One participant emphasized the importance of being able to give meaning - or a name or diagnosis - to their experience, as this also provided other opportunities or benefits such as contact with fellow sufferers: *"But also I could not give a name to what I experienced, there were no fellow sufferers and there was also no diagnosis."* (Anna, T3). Social factors in general were deemed crucial for well-being: *"People are very important, how limited it is, people are very important."* (Anna, T3)

Despite their efforts to (re) gain agency in coping with their pain, many women recognized the importance of having doctors and specialists who were capable or willing to assist them in this journey. While navigating the healthcare system, participants often encountered healthcare providers either expressing significant disbelief or mistrust regarding the authenticity of their pain complaints, demonstrated a lack of knowledge about fibromyalgia, or displayed a general unwillingness to help. For many participants, finding "the right" healthcare provider was a challenging, yet essential endeavor. Participants identified several factors contributing to someone being deemed "a good provider".

Participants emphasized their awareness that the condition is not curable, raising the idea that they hold realistic and modest expectations towards healthcare. However, they expressed a desire for doctors to **continue standing alongside them** and **assist in exploring treatment modalities** to try out, both biomedically and psychosocially. *"If you see that your doctor is doing the best he can and helps searching and further helps digging."* (Diana, T14); *"It is a really nice psychiatrist, so uhm.. with a lot of understanding and also someone who gives tips/advice and who thinks along."* (June, T12). In the two latter quotes, it is evident that providers who assisted in exploring potential treatment strategies were considered highly valuable. *"And now I ended up with an osteopath. I have been doing this for 2 years now, but it is also so interesting and compelling, what I learn and what that man can tell me and what he knows. And if it will cure me, that I don't know, but in the meantime, you are busy with something positive."* (Anna, T3). This participant emphasized the value of interacting with healthcare providers who could provide information. While such interactions may not have led to a cure, they contributed to maintaining a positive attitude and avoiding feelings of powerlessness.

Related to this, it was also suggested that having a few consultations in per year with a specialist for follow-up and to listen to their story would be helpful. Healthcare relationship continuity was considered highly beneficial, emphasizing the benefits of having someone on their side whom they could approach or schedule consultations with, as expressed by Olivia: *"Somebody who is on your side, whom you can approach or book a consultation with, would be helpful"* (Olivia, T13). We argue that this stood in contrast to the medical healthcare system, which primarily focuses on healing and problem-solving rather than providing continued guidance.

Furthermore, participants also valued a humane, personal, and equal relationship with their healthcare providers, where they did not feel like just a number: *"(name doctor) was a super good one, it was a lovely person that was also humane."* (Amy, T1); *"And I know, rheumatologists and specialists in physical medicine see so many people that you are a number in the long run and that is something I don't want to be." (T6); "Uhm, someone, with whom I can also build a trusting bond. Despite the fact whether it really cures or not. That is just really valuable."* (Anna, T3)

In this regard, listening to participants' narratives and wishes in treatment was perceived as important: *"But I always discuss the real medication with my healthcare practitioner. Now, I am also weaning off from medication, really slow, since September. So, with the help from, uhm, I said "I want* *to wean off", "oh yes that is not a bad idea", uhm and she supports me. Next time she asks "and how is the weaning off going?"."* (Mia, T4)

In sum, participants valued mutual interaction and discussion with their healthcare providers, highlighting the importance of a balanced power dynamic between patient and provider, as expressed by Amy: *"But there is interaction. It is not like "I am a doctor and you will shut up"."* (Amy, T1)

Consistent with previous research, participants highlighted the importance of validation of their pain condition by healthcare providers, a sentiment echoed by all participants. Acknowledgement of pain and understanding were deemed crucial, as well as avoiding dismissing complaints as solely psychological or psychogenic. This is illustrated in the following quotations: *"My physiotherapist says then "Yes, everybody has his pain, you may also not deny your pain."* (Alice T9) and *"and usually, they push into the direction of depression, because for them it is something between the ears. Yes okay, it is between them, but from the brain. But for them it is psychological."* (Mia, T4). In the absence of clear pathophysiology and appropriate treatments - often perceived as stigmatizing - validation becomes one of the most important aspects an individual can experience.

Further, participants perceived providers educating themselves about fibromyalgia as validating. Validation, in general, resulted in the continuation of healthcare relationships, while perceived invalidation led to discontinuation of the relationship on behalf of the patient. For instance, Alice mentioned: *"I kept going to the same psychiatrist because back then, uhm, that person educated himself or he has looked things up and he understood it then. And he is also specialized in sleep."* (Alice, T9,-798)

In summary, participants shifted from a treatment model focused on curing to a coping model, focused on strategies to manage their complaints. These coping strategies are embedded in a biopsychosocial perspective, while they continue to search for a biomedical solution. A highly important factor is finding "the right" healthcare provider with whom your illness and coping model align.

Discussion

The findings of this qualitative study describe how women with fibromyalgia navigate the healthcare system while developing an illness and treatment model for their pain. Two main themes were constructed: 1) the challenges encountered in developing a comprehensive illness and treatment model within a still biomedically oriented healthcare system; 2) the process of participants (re)gaining ownership and agency over pain management by constructing a personal illness and treatment model.

Developing personalized illness models that can guide treatment plans and, alleviate feelings of uncertainty (Leventhal 2016; Hagger 2022, Barker, 2002) is crucial for individuals with fibromyalgia, given the lack of identifiable causes and explanations. The current findings revealed that the sense of abandonment by the healthcare system, as noted in previous studies(Boulton, 2019; Doebl et al., 2020; Eccleston & Crombez, 2007; Hayes et al., 2010; Mengshoel et al., 2018; Sim & Madden, 2008) remains a persistent and significant issue today. The absence of clear illness and treatment models is inherently stigmatizing, as participants perceived themselves as different from other patients, and felt that their needs were inadequately addressed. Diagnostic uncertainty, though common in healthcare (Dahm et al., 2023), presents a unique challenge in fibromyalgia. Unlike other conditions where a diagnosis often establishes a well-defined care plan, fibromyalgia lacks this predictability, leaving both patients and providers without a clear or reliable path for treatment and management.

In the absence of a clear illness model, the treatment model for fibromyalgia remains ambiguous, lacking specific treatment guidelines. Consequently, the treatment still primarily focuses on medication, including potent opioids, despite their contra-indications and limited effectiveness (Painter & Crofford, 2013). This contrasts sharply with participants' willingness to exploring diverse psychosocial and alternative treatments, as highlighted in the current study. Remarkably, research suggests that women with chronic pain more often take prescribed antidepressants (Thunander Sundbom & Hedborg, 2019), because their complaints are more often perceived as psychological compared to men (Schäfer et al., 2016). This underscores gender disparities in healthcare (Hohmann, 1989; Morgan et al., 2016; Thunander Sundbom & Hedborg, 2019). Further, participants articulated a deficiency in professionals' knowledge of fibromyalgia, according with previous research (Kumbhare et al., 2018). These dynamics resulted in feelings of powerlessness, both in participants and professionals, aligning with previous research (Sim & Madden, 2008). Nevertheless, participants in the current study indicated that doctors often failed to recognize their sense of powerlessness, suggesting that they were unwilling to give up their authoritative position. Instead, they often terminated the healthcare relationship, perhaps to alleviate their own feeling of powerlessness. We believe that healthcare providers addressing their own feelings of powerlessness during encounters could improve the therapeutic relationship and guidance.

Previous research showed that healthcare providers experienced frustration or even antipathy in treating fibromyalgia (Briones-Vozmediano et al., 2013; Doebl et al., 2020; Hayes et al., 2010). Research also showed that doctors perceive individuals with fibromyalgia as more challenging than those with rheumatoid arthritis and may be more hesitant to accept them into their care (Aloush et al., 2021). This reluctance may be influenced by "associative stigma," where individuals are stigmatized due to their connection with another stigmatized individual, whether formally (healthcare relationships) or informally (social network). Being associated with 'difficult' patients can, in itself, pose challenges for healthcare providers. A previous study on associative stigma in mental health professionals has shown an association with lower job satisfaction, lower patient satisfaction and higher patient self-stigma (Verhaeghe & Bracke, 2012). Treating fibromyalgia does not entail curing it, but rather improving quality of life, which may make physicians perceive their work as less distinguished or satisfying.

In the current study, it was examined how women with fibromyalgia coped with the lack of guidance from healthcare. Several women shifted from a passive to an active role one by seeking ~~for~~ answers on their own. In other words, most of them took greater responsibility for shaping their own illness and treatment models. Participants experienced this as a transformative process with a mix of challenges and personal growth. This shift of self-empowerment was evident at various stages of their illness and treatment journey. Some women initiated this shift early on by advocating for a diagnosis. Almost all women engaged in self-education, a behavior highlighted in previous research (Raymond & Brown, 2000). However, findings emphasize that participants were motivated by the need for a coherent illness and treatment model, prompting them to adopt coping strategies and to develop an illness and treatment model themselves. Interestingly, participants embraced a more biopsychosocial perspective, recognizing the role of both biomedical and psychosocial factors in the illness' causes and treatment, which facilitated to acceptance. Notably, participants and their romantic partners perceived the pain condition as a shared problem for which they collaborate, engaging in what is known as dyadic coping (Helgeson et al., 2018). The limited effectiveness of treatments for fibromyalgia (Garcia-Campayo et al., 2008) may stem from their inability to enhance patient agency. Instead, these treatments often place the power in the hands of healthcare providers, making the patient a passive recipient of care. It is possible that fostering agency throughout the treatment trajectory could be key to improving functioning, but further research is needed. Agency may be particularly important for conditions lacking a clear biomedical treatment, such as fibromyalgia, which necessitates a more complex biopsychosocial approach. A similar qualitive study on chronic fatigue syndrome found that participants developed a more complex perspective on causality and illness, leading to a greater sense of agency (Bakken et al., 2023). This dynamic aligns with the Self-Determination Theory (Deci & Ryan, 1985, 2000), which emphasizes the basic needs of autonomy, competence and relatedness. Autonomy refers to the need to feel in control of one's own actions and decisions, competence involves the need to feel effective and capable in one's activities, and relatedness pertains to the need to feel connected to others. When treatments fail to address these core needs, they may be less effective. Reflecting on participant's narratives of agency, it is apparent that certain preconditions - such as social support, financial stability, and cognitive abilities - are necessary for demonstrating agency.

A key challenge in participants' self-constructed treatment model was finding providers whose perspective aligned with theirs, allowing for the establishing a shared understanding of illness and treatment. Participants emphasized the need for providers who are willing to collaborate in exploring different treatments options, even when acknowledging that many approaches may prove ineffective. Moreover, interactions with specific healthcare providers shaped the development of illness and treatment models. For instance, providers with a biopsychosocial approach influence patients to adopt similar perspectives in their personal models. Participants also highlighted the importance of professionals who can manage the uncertainty inherent in treating conditions like fibromyalgia, which echoes findings from a previous study on fibromyalgia (Durif-Bruckert et al., 2015) and low back pain (N. Costa et al., 2023).

In contrast to participants who felt empowered, a few women in this study expressed a sense of uncontrollability. These findings suggest the presence of two groups: those who feel empowered and those who continue to feel powerless. They ceased consulting healthcare providers due to the belief that nothing and nobody could help them. These women exhibited lower well-being than women who felt empowered, suggesting that gaining agency may be key to improved functioning. Notably, these women had not pursued higher education, potentially reflecting lower health literacy. The WHO even depicts health literacy as undertaking actions that demonstrate patient agency (Ahearn, 2001), highlighting the close association between these concepts (Hunter et al., 2015). Additionally, lower socio-economic status (SES) could be a contributing factor, though multiple relevant variables were not measured in this study. Previous research has shown that individuals with lower SES are less inclined to seek health information and feel less capable of obtaining it (Richardson et al., 2012). These women also lacked an elaborate social network for support. Hunter and colleagues argued that gaining agency in healthcare is intertwined with patients' individual circumstances, resources, and access to supportive networks(Hunter et al., 2015). Nevertheless, it is crucial not to label the women who remained feeling powerless as "difficult patients" and those who demonstrate autonomy as "easy patients". Previous research suggests that healthcare providers may perceive individuals with fibromyalgia as more challenging than those with rheumatoid arthritis (Aloush et al., 2021). Another qualitative study found that individuals with fibromyalgia are often perceived as complainers (Briones-Vozmediano et al., 2018). In line with this, one participant in the current study expressed disdain for fellow patients who “embraced their condition” and stopped pursuing treatments, indicating the presence of in-group stigmatization.

Several clinical implications can be drawn. Participants emphasized the importance of continuity in healthcare relationships. Establishing a structured trajectory, including consultations with the same specialists multiple times a year, could help professionals managing the frustration often associated with treating fibromyalgia. A narrative review has highlighted the lack of a standardized care model for fibromyalgia (Doebl et al., 2020). Also in Belgium, healthcare approaches to fibromyalgia vary, with some settings adopting an evidence-based plan, while others lack a consensus-driven approach. The findings of this study may also be relevant for other primary pain conditions, such as migraine, irritable bowel syndrome, which face similar challenges. Patient-centered care can support individuals with fibromyalgia in developing personalized illness and treatment models, ultimately improving their long-term well-being (Langford et al., 2018).

The concept of social prescribing, a community-based approach aimed at connecting individuals with health, social, or practical needs to local (i.e., accessible) providers of non-clinical services, has garnered increased attention (A. Costa et al., 2021; Pilkington Karen et al., 2017) (p. 2). While quantitative studies assessing its impact of social prescribing on mental, physical, and social health have yielded mixed findings, qualitative research indicates improvements among participants (N. Costa et al., 2023). Social prescribing may offer benefits for patients with fibromyalgia and chronic pain by streamlining access to resources. Currently, many fibromyalgia patients navigate services independently, but social prescribing could help them access support more efficiently. For instance, group-based exercise programs, which are important for individuals with fibromyalgia. Participating in group activities, such as exercise, may enhance well-being and functionality more effectively than solitary activities. This approach could be particularly beneficial for those who feel powerless and need additional support to regain a sense of control.

A few limitations should be considered. First, the results may not be transferable to countries outside Belgium as healthcare systems can differ. Second, participants were recruited from a patient organization, which may introduce selection bias as these individuals may be more empowered and proactive in managing their condition. Finally, all participants were white, limiting the transferability of the findings to individuals from other racial backgrounds due to the intersecting nature of pain-related experiences (Boerner et al., 2024).

Several avenues for future research can be formulated. First, investigating the experiences of men with fibromyalgia may provide insights into potential differences in power dynamics and coping strategies compared to women. Second, the role of socio-economic status (SES) in gaining agency in the illness and treatment trajectory warrants deeper investigation as individuals with lower SES may be more vulnerable to feelings and thoughts of powerlessness. Understanding how gender and SES shape fibromyalgia experiences could help develop targeted interventions to address healthcare inequalities. Finally, future research into the effectiveness of social prescribing programs for fibromyalgia patients could provide valuable insights into their impact on treatment satisfaction and quality of life.

In conclusion, the findings highlight the dominance of a biomedical orientation within the healthcare system, which often leaves women with fibromyalgia feeling trapped within a complex web of inadequate illness and treatment models. As a result, many women took on agency, while others felt powerless, underscoring the need for additional support. Overall, these results emphasize the importance of fostering patient agency in developing personalized illness and treatment models, highlighting the need for more comprehensive and patient-centered care in managing of fibromyalgia.

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Table 1. *Semi-structured interview schedule.*

Opening question
We will start with a general question. Can you tell me something more about the pain complaints you experience?
PROMPTS: How would you describe the pain you experience? Where do you feel the pain? How does the pain affect your ability to function in daily life?
Key questions
Can you tell me something about what you think could be the cause of your pain?
PROMPT: Can you describe what might have triggered the pain?
What do you think could be an effective treatment?
Did your thoughts on these things (causes and treatments) change throughout the years?
PROMPT: What do you think was the reason for this change?
Do your current opinions (mis)match those of your healthcare providers, and have they always (mis)matched?
PROMPTS: How did you experience this? Did this affect your relationship?
Closing questions
(Providing summary of the content of the interview) Did I correctly describe what you discussed today? Is there anything missing?
Are there any questions you would like to ask me? Or things you would like to know?

Table 2. *Sociodemographic and clinical characteristics of the sample.*

Participant alias	**Age**	**Education**	**Marital status**	**Employment status**	**Years since FM diagnosis**
1 Amy	41	Higher secondary	Married or cohabiting	Full invalidity allowance	18
2 Sarah	57	Lower secondary	In a relationship (not cohabiting)	Full invalidity allowance	4
3 Anna	53	Higher education – bachelor	Married or cohabiting	Full invalidity allowance	25
4 Mia	51	Higher vocational	Married or cohabiting	Full invalidity allowance	10
5 Marie	52	Higher secondary	Single	Full invalidity allowance	14
6 Julia	45	Higher education – bachelor	Married or cohabiting	Full invalidity allowance	17
7 Kim	68	Higher education – bachelor	Divorced	Retired	11
8 Daisy	53	Higher education – bachelor	Single	Full invalidity allowance	9
9 Alice	54	Higher education – bachelor	Married or cohabiting	Full invalidity allowance	13
10 Lily	50	Higher education – bachelor	Married or cohabiting	Partial invalidity allowance and partially working	4
11 Kate	24	Higher vocational	Married or cohabiting	Partially working	3
12 June	41	Higher vocational	Married or cohabiting	Full invalidity allowance	6
13 Olivia	25	Higher secondary	Single	Partial invalidity allowance and partially working	4
14 Diana	48	Higher education – master	Married or cohabiting	Working	15
15 Grace	34	Higher vocational	Married or cohabiting	Working	16

FM= fibromyalgia