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Fibromyalgia as a Transparent Disease

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Abstract: Background: Fibromyalgia patients suffer from widespread chronic pain throughout the musculoskeletal system. There are no apparent clinical visible symptoms, and the syndrome lacks a clear medical explanation. Female fibromyalgia patients often feel they suffer from a transparent disease which is not acknowledged as an illness by their social circle. Hence, they are often exposed to skeptics and critics. One of the challenges fibromyalgia patients faces is to convince their surroundings that they are in pain and accept the presence of the invisible disease and the chronic pain in their lives. A multidisciplinary Fibrotherapy treatment model, implemented at the Ezra Le'Marpeh Rehabilitation Center, supports female fibromyalgia patients through a holistic mind-body approach, delivered in three 10-week cycles totaling 30 weeks of treatment. The research aims to understand the experiences of female fibromyalgia patients who perceive themselves as suffering from an invisible disease and the personal and familial aspects of transitioning from lack of acceptance to coping with reality and adaptation. **Methods**: We interviewed 16 female fibromyalgia patients in Israel and qualitatively analyzed the data using the Grounded Theory approach. **Results**: Following participation in the program, the fibromyalgia patients accepted the presence of the disease in their lives and changed their attitude toward the disease and its consequences. **Conclusions**: As fibromyalgia symptoms are invisible and can suddenly burst into their lives without warning, female fibromyalgia patients often face skepticism from their social circle and have self-doubt. Therefore, participating in holistic intervention programs may improve how they accept the disease and come to terms with its existence by taking a proactive coping approach.

Keywords: Fibromyalgia; Fibrotherapy; invisible disease; transparent disease; acceptance

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Introduction

Fibromyalgia (FM) is characterized by widespread chronic pain throughout the musculoskeletal system [1], in addition to symptoms such as fatigue, sleep disturbances, and cognitive and somatic irregularities [2,3]. FM is part of a spectrum of unclassified syndromes [4,5] and is considered a functional somatic syndrome due to the absence of a clearly identifiable medical basis or its categorization as a somatization disorder [5].

Invisible diseases encompass a range of health conditions that lack immediate visibility to external observers. These diseases encompass diverse maladies including chronic pain, autoimmune disorders, neurological conditions, and mental health ailments. The term "Invisible Disease" underscores the reality that individuals grappling with debilitating illnesses might not externally manifest any discernible physical indications. This inherent concealment frequently engenders misconceptions and misunderstandings regarding the illness, potentially resulting in discrimination or inadequate support from others [6–8].

One of the challenges of invisible diseases is that they are often difficult to diagnose. The absence of visible symptoms can lead to protracted diagnostic processes [9], causing patients frustration and stress as their condition and symptoms may be downplayed or disregarded by medical professionals [10]. The lack of research in this domain underscores the continued need for the medical community to enhance its understanding of various invisible diseases, which can compound the diagnostic journey.

An invisible disease could also result in a lack of support and comprehension within the immediate social context of the patient. For instance, an individual enduring chronic pain might outwardly appear unaffected and capable of routine activities, yet this façade belies their internal distress, necessitating accommodations and support to manage their symptoms [11,12].

There is abundant evidence of stigma against people with invisible chronic diseases. Stigmatization is influenced by many issues, such as lack of knowledge or misdiagnosis, moral judgments, and incorrect perceptions about the disease [12–14]. FM patients frequently grapple with a situation where the acknowledgment of pain as a genuine pathological condition is contentious [11]. Despite empirical evidence substantiating pain's impact as a disease [15,16], a definitive delineation of its pathological essence remains elusive. Therefore, establishing *pain* as a disease is essential to generate awareness of this global health problem that does not receive the requisite attention [15].

The challenge of FM is the need for more clarity regarding its status as a defined disease. A disease is a deviation from the norm, a recognizable phenotype with measurable symptoms and established causative factors. Therefore, if etiology and pathophysiology are required to define a disease, FM's ambiguous cause places it outside the realm of disease classification [17,18]. On the other hand, the array of clinically identifiable symptoms and behaviors are often associated with distress and impairment in personal functioning, enabling FM to be defined as a disorder [5]. As FM symptoms are often hidden from view and can appear suddenly, patients with FM frequently encounter skepticism and feel isolated since "outsiders will not understand it. "Skepticism can arise from the immediate environment, family, friends, and workplace. Research conducted in Canada has shown that the problem in the job market is often the level of awareness of the employer [19]. The "outsider" can also be the treating physician. Women have often been diagnosed with FM by a rheumatologist, while another healthcare provider, such as a family physician, may have doubts about their diagnosis [20].

A common thread in the FM patient experience and coping mechanism is the prevailing sense of uncertainty, particularly during disease exacerbations. Uncertainty compounds the psychological burden of managing a chronic ailment. Heightened pain exacerbation frequently corresponds to coping difficulties, with women afflicted by severe pain encountering particular challenges in managing FM symptoms. Moreover, greater pain severity in women tends to magnify these challenges over time. The pivotal role of uncertainty is evident in these dynamics; heightened uncertainty amplifies the complexity of symptom management, rendering patients more susceptible to pain exacerbation. Elevated levels of uncertainty also correlate with diminished coping abilities, leading to heightened emotional avoidance, which in turn associates with escalated pain and fatigue levels. Women who struggle to process or articulate their emotions often report elevated pain intensity [21]. Emotional avoidance is associated with higher pain and fatigue levels, and women who could not process or describe their emotions showed higher pain intensity [22].

Many patients with FM do not fully understand their condition, which leads to cognitive difficulties in pain perception and inadequate coping strategies. In this context, the selection of coping strategies is influenced by whether the individual perceives an event or situation as a threat or a challenge [23,24]. Frequent use of maladaptive coping strategies, negative emotions, and lower performance are associated with a perceived threat. In contrast, perceiving a situation as challenging leads to adaptive coping strategies, positive emotions, and higher performance [25].

The Fibrotherapy Model

Multidisciplinary interventions aimed at increasing holistic physical fitness and subjective well-being are particularly recommended for patients with low physical fitness [26,27]. In this context, the Fibrotherapy (FT) treatment model utilized in this study is implemented at the Ezra Le'Marpeh (Assistance in Recovery) Rehabilitation Center in Shderot under the leadership of Rabbi Elimelech Firer. The center's team supports female FM patients (FFMPs) by applying a holistic mind-body model, which combines physiotherapy, Pilates, hydrotherapy, emotional support group therapy, gardening therapy, cooking therapy, and a unique ceramic workshop that summarizes their process. The treatment is delivered in three 10-week cycles, with each stage providing a different aspect of therapy. In total, the patients receive 30 weeks of treatment.

The exploration of FM as an invisible disease and the investigation of chronic pain as an independent pathological condition represent novel and inadequately explored areas within scholarly discourse. It is essential to acknowledge that within the framework of the Israeli healthcare system, the official recognition of FM as a legitimate disease warranting disability benefits has occurred only recently. The historical absence of such recognition may have contributed to the dearth of research endeavors that establish connections between the inconspicuous nature of physical symptoms and the broader issue of societal acceptance of the ailment. The primary objective of our research endeavor was to meticulously scrutinize the concealed nature of pain in the context of FM and its ramifications on the social milieu surrounding individuals afflicted by FM, herein referred to as FFMPs. Central to this examination was determining whether FM is perceived as an invisible disease from the vantage point of FFMPs. The pioneering nature of our study is evidenced by its capacity to offer a fresh lens through which to perceive FM, consequently engendering an innovative intervention approach that challenges prevailing perspectives.

Material and Method

The current study is part of mixed-methods research to examine various coping and coping resources among FFMPs residing in a security-threatened area. Through qualitative analysis, we found that beneath the surface, there are additional dimensions that have not been adequately explored concerning the characteristics of the disease itself and the FFMPs and their families' attitude towards the disease, the absence of symptoms, and the experience of chronic pain as a constant presence in their lives. Analysis of the narratives revealed that similar to the changes in the FFMPs' medical measures and their resilience and coherence measures [28–30], there were also changes in their attitude and acceptance of the disease. These narratives initially brought forth a primary theme that had received little attention in the context of FM, namely the encapsulation of this syndrome within the realm of invisible diseases.

The research framework is based on the narrative of the disease experience, and therefore, we chose the phenomenological-narrative research method, which is part of the qualitative research method. The phenomenological researcher does not study reality but how the research subjects perceive reality. Therefore, the data were collected through in-depth interviews [31]. Qualitative research assumes narrative discourse is the best way to present human experiences. The phenomenological approach is suitable as a research paradigm for this work since phenomenology offers a transcendent search for the 'essence' of the human experience or the fundamental central meaning of the experience. The phenomenologist investigates the phenomenon itself. The term 'phenomenon' is a general concept that describes the proper understanding the subject has about things and events in the world. The phenomenon is examined in the sense of an event experienced subjectively. A phenomenon encompasses perceptions, memories, imaginations, cognitions, and more [31].

Narrative work is how narratives are constructed, communicated, sustained, or reshaped [32]. Narratives incorporate temporality, social context, complex events, and evaluative interpretation, all of which together form a coherent story in which the narrator or protagonist is an active agent in the story [33]. The acquisition of meaning for an illness has gained increasing attention among health researchers. It is argued that the meanings individuals attribute to life crises influence their coping [34]. Therefore, the experience of illness is the subject of the current research and was investigated using phenomenological concepts–in terms of the meaning ideas and actions hold for individuals in a particular situation. It should be noted that in the original study, specific questions related to FM as an invisible disease were not asked. Nevertheless, this phenomenon was reflected in each interview's discourse.

Participants

We interviewed 16 Jewish FFMPs, ages 19–75, who were clinically diagnosed with FM at least one year before the research. These patients were part of the study described in articles [28–30] and participated in all 30 weeks of the FT program at the Ezra Le'Marpeh Center. The recruitment was conducted among FFMPs who agreed to participate in the qualitative part of the research and share their experiences and coping strategies.

Data Collection

The primary researcher conducted the interviews over the phone during the COVID-19 pandemic in 2020. The anonymity of the interviewees was carefully maintained during the recording and transcription of the interviews.

Data Analysis

For data analysis, we employed the Grounded Theory approach in which codes and categories emerged from the data. We conducted the thematic analysis [35], which involves identifying, categorizing, and describing patterns within the raw material of the findings. This process includes clearly defining the unit of analysis, constructing a hierarchy among the themes and sub-themes, and attempting to develop a theoretical model that summarizes and explains the researched reality [36]. Qualitative data analysis in research is an integrated process of content deconstruction and reconstruction [32,37]. Such an analysis process is based on the search for salient components that recur within the collected data.

Qualitative data analysis is a process of sequencing and constructing the information collected to interpret and understand its meanings. Data analysis is carried out using the thematic analysis method. Qualitative research ensures reliability through different strategies (Tzabar-Ben Yehoshua, 2016). In order to ensure reliability in this research, resources and time were invested in obtaining consistent data. Systematic data collection was emphasized, multiple case studies were conducted, and additional individuals (the supervisory team) were consulted to evaluate the results and the research process and provide feedback during the analysis and writing process [31,38].

Results

A cohort of 16 female patients in the Gaza Strip, facing security threats, who underwent the FT intervention, also participated in the quantitative research study described elsewhere. All interviewees highlighted their challenges in experiencing invisible chronic pain without external or internal clinical symptoms and their family's difficulties. After the intervention, we noticed a significant change in their attitude toward chronic pain and their coping mechanism with FM. Four main themes emerged from the results, which are detailed below.

"I can't accept a pain which I can't explain"

In general, diseases are accompanied by various physical symptoms. When it comes to pain, it is usually attributed to a specific illness or injury. In the case of FM, however, there are no apparent physiological symptoms except for the sensation of pain at various trigger points. The absence of observable symptoms that could indicate a distinct disease initially led to a lack of self-acceptance of the and confusion mixed with uncertainty:

> "I had pains in my body which I couldn't define. It was difficult living alongside this uncertainty. It took me a long time to vocalize the word 'fibromyalgia' because I mainly didn't know how to perceive it" [P1].

> "I would try to remember if perhaps I was injured or strained something. I searched all over my body for bruises but couldn't find any" [P2].

In many cases, the final comprehension that the cause of the pain was FM originated in external sources rather than clinical diagnosis:

> “When the symptoms started, I didn’t understand what was happening to me. I felt unwell, but nothing was visible. All the medical tests I have undergone for years didn't indicate something was wrong. By chance, while watching TV, I saw Professor Buskila talking about the symptoms of fibromyalgia I experienced” [P3].

In addition to the absence of symptoms, the patients felt that they had to cope with a new condition–chronic pain–day in and day out, and this sudden recognition without any warning posed difficulties in accepting the disease:

> “Until that moment when I read about it and understood that I have it, for me, fibromyalgia was a disease that women invented to avoid working. As someone who always worked and gave more than 100 percent, I couldn't understand how fibromyalgia was now connected to my world. Before I realized that I had fibromyalgia, I used to ask my husband at night, ‘Does your whole body ache when you lie in bed?’ and he would answer no. I thought it was because I worked so hard” [P5].

The lack of understanding and certainty about what they experienced also led to self-criticism and frustration towards their bodies. The feeling that the body betrayed them resulted in changes in their mood:

> “My body sent me a lot of singles, but I blatantly ignored them and dealt with each of the pains I experienced in a precise and medical manner. I was angry and frustrated with my own body, a feeling that it betrayed me. I feared that disease would somehow suggest that I was lazy. I didn't understand what was wrong with me, which crushed me emotionally rather than physically” [P6].

Since many of the patients doubted the existence of a clinical disease before they were diagnosed or realized that they had FM, they began to question their mental stability:

> “I thought that perhaps I had a mental problem, so I started going to a psychologist” [P2].

"I have a transparent disease–nobody believes me"

The first thing that patients encountered when they began to experience pain was a lack of acceptance from their family regarding their disease:

> “When I lie in bed due to my pain, they think maybe it’s the flu, or I caught a cold. They wouldn't believe it may be anything else since they claim there is no such thing as 'fibromyalgia” [P8].

> “My husband and children didn't believe it at first and would ask: 'Why are you sleeping all day long?” [P4].

> “My father thought I was making up the disease to receive disability benefits” [P5].

The patients reported a lack of trust in their social circle due to the absence of prominent symptoms: the feeling that their disease is transparent, and nobody sees it; consequently, not believing they are sick left them feeling lonely. They did not feel they were getting support from their immediate environment, including their family members:

> “From a family perspective, although everyone knows I have FM, I still receive comments like, ‘Why did the pains start again?’ And I don't understand what they mean by ‘started again’ since I tell them the pain is always there. It feels as though they don’t listen to me. It’s like talking to walls; sadly, I know I won't get strength from there” [P8].

> “It’s hard to explain all the time. When they (family members) ask, ‘Where does it hurt?’ It's hard to explain to someone who doesn’t understand what you're going through. Because when a person says they have the flu, there are symptoms, fever, and specific muscle aches. People understand that. Nevertheless, people don't know how to relate to fibromyalgia” [P10].

The skepticism and lack of trust that the immediate environment expressed towards the presence of natural and tangible pain, and the unwillingness to be the focus of criticism and judgment, often led the patients to hide their suffering from their family members and pretend to be healthy despite the suffering:

> “I put on a mask as if everything is fine, and I smile, but inside, everything hurts” [P6].

> “Since it’s hard for my family to accept it, I suffer quietly and try not to show that I have aches at home” [P4].

> “My brothers criticize me and say things like, ‘You used to be active, and suddenly you turned into a couch potato’ That’s why I don’t talk about my disease because I don’t want to be judged” [P7].

One characteristic of the environment’s response to the presence of pain without physical symptoms was the claim that the patient was experiencing mental difficulties:

> “When telling people that I was in pain, the typical responses would be: ‘Enough, you’re just being lazy, you’re making up excuses, there’s something wrong with you mentally, go seek treatment’ [P11].

> “The feeling I received from my immediate environment was that I have a psychological problem if I have FM. I still believe people often perceive it as a psychiatric condition when it’s not always the case” [P12].

> “Until I was diagnosed and knew what I had, I felt that there was no point in talking about it too much or sharing with people what I was going through because, once again, they would tell me that there was something wrong with my head or something” [P13].

The patients often struggled with a sense of devaluation, coupled with their diminishing productivity, while their immediate surroundings disregarded their pains and the distressing sensations that they conveyed:

> “I felt as if I wasn’t taken at face value because I kept saying that I was in pain, and no one believed me” [P2].

> “It was difficult to cope with the decline in my work performance and inability to explain it” [P13].

> “Since my pain is invisible, when I try to explain what’s happening to me, my children would say, ‘Stop with these thoughts; you’re putting things into your head; it’s just nonsense, you’re overreacting, you can handle it; how could it be that your leg is hurting so much, what, are the bedsheets scratching you?” [P14].

> "You can't go around all day saying 'I'm in pain' because, at some point, no one is listening... It's hard to live with someone in pain 24/7" [P7].

Acceptance After Intervention

After they participated in the FT program, there was a significant change in the attitude of the patients toward their disease and pain. The most vital agent of change was acceptance. Acceptance manifested primarily as accepting the presence of pain as part of their daily life:

> "Today, I have come to terms with the fact that I experience an occasional pain" [P4].

> "The comprehension that it's a matter of 'ups and downs'–feeling better at times and worse at others, even though I perform in the same manner. It means that my physical experiences are not what I want them to be but what they are now" [P14].

> "Acceptance grew in the face of the realization that it won't get easier, so I have to learn to ease myself within the existing limitations and circumstances" [P6].

Accepting pain as part of the routine led to adaptation and better attention to the body. As a result, the patients also learned to slow down and accept the fact that they can no longer function as they used to and come to terms with this understanding:

> "In the past, I never rested, even when I was tired. Now I tell myself to listen to my body" [P13].

> "If in the past, I hid behind a smile and conveyed that everything was fine, today I accept that I have a disability" [P6].

> "After participating in the program (FT), I also know when to stop, look at the clock, and go to sleep at a specific time, not when I'm already collapsing from fatigue as I used to do in the past" [P15].

Acceptance of chronic pain also led to a decrease in the prominence of the disease among the patients. It no longer occupied a full presence and controlled their entire daily routine but became something that they learned to coexist with:

> "I simply don't think about my disease. In the past, I was preoccupied with the pain all the time. Today, I'm not preoccupied with it at all. I don't give fibromyalgia a place. And if I experience specific pain, I rest and allow myself the space for healing rather than the space for being ill" [P11].

One characteristic of adapting to pain as part of the routine is the ability to rely on family and acknowledge the need for assistance:

> "In the past, I felt like I had to be Wonder Woman all the time and function even when I didn't feel well. Today, I allow myself to get into bed and tell my family that no one else will if they don't prepare their meals. Even my spouse now takes on many of the tasks that used to be mine at home, and I allow and accept that" [P3].

> "I learned to ask for and accept help from others. I did everything by myself in the past, and when I couldn't do it all anymore, it frustrated me. I ask for help today and feel much better about it" [P16].

Coping with Fibromyalgia After Intervention

Coping after the intervention is manifested in two aspects: taking control and engaging in proactive healing activities acquired through the FT program:

> "I exercise every day, practice Pilates and bone-building exercises. Following participating in the program, I acquired tools when I fell into difficult situations. I have gained psychological tools no less than physical ones" [P3].

> "I think that primarily, I regained control over my body. I understood it's not a temporary diet; it's about living life to the fullest, not stopping for a second and focusing only on a specific corner" [P14].

Discussion

Coping with chronic diseases is something that most, if not all, humans go through during their lives. When coping with a chronic disease, the cards are reshuffled because, as opposed to non-fatal diseases with a short and limited life expectancy, chronic diseases often have no horizon for recovery. Chronic disease becomes a part of the patient's life from the moment of diagnosis and is likely to accompany them infinitely. The literature is abundant with studies that show a clear correlation between coping with a chronic disease and emotional and psychological aspects. Many studies have addressed the emotional and psychological foundations underlying coping with FM [39–43]. However, our study is unique because it touches on two important aspects of pain and FM as an invisible disease. Therefore, the study can serve the academic and public health fields, FFMPs, and their immediate environment. The study is indeed scientific research, but the insights and conclusions that arise from it can serve the broader public as it sheds light on points that have not been identified before. The Fibrotherapy model is an innovative holistic treatment program used exclusively in the "Ezra Le'Marpe" center. Therefore, our study can serve as a basis for planning similar interventions to alleviate the lives of FFMPs. Another significant strength of the study is that the primary author served as a therapist at the "Ezra Le'Marpe" center, contributing to the study's validity and potential for practical application.

Our research strengths also entail limitations. Since it was conducted within a single unit of a specific therapeutic institution, the findings cannot be generalized to other FM treatment programs, as the Fibrotherapy method is unique to the "Ezra Le'Marpe" center. Furthermore, the research was conducted among women exposed to ongoing security threats. This constant threat provides fertile ground for various psychological and emotional coping mechanisms, even among healthy individuals with FM. Therefore, some of the symptoms observed in the study, which were influenced by existential fear, may appear among other individuals who are not afflicted with FM but are under sustained security threats. On the other hand, some of the symptoms observed in the study may not appear among other FFMPs who are not under security threats. Hence, the research results serve as evidence of a particular environmental context, and the only way to compare it with other environments, such as those without security threats, is through comparative and follow-up studies.

Conclusions

Since the symptoms of FM are invisible and fall under the category of "invisible diseases" that can flare up suddenly, FFMPs often face skepticism from their social circle and physician. Therefore, exposing FFMPs to intervention programs is essential, which may improve their quality of life, worldview, and perception. Disease management is a proactive and inspiring action. Hence, taking measures to cope and adopting a long-term perspective are actions that can contribute significantly to the self-worth of FFMPs and, in turn, enhance their social value.

Ethics Approval: The Ariel University Ethics Committee approved the research. Concurrently, approval was obtained from the Ezra Le'Marpeh Rehabilitation Center in Shderot, Israel, to research and examine the model developed there for treating female fibromyalgia patients.

Informed Consent: The interviews were recorded, transcribed, and served as part of the research's credibility and reliability assessment. Confidentiality and privacy concerns were addressed by discreetly preserving the personal details of the participants discreetly to protect their rights.

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List of abbreviations

FM–Fibromyalgia
FT–Fibrotherapy
FFMPs–Female Fibromyalgia Patients

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