



'This illness affects not only me': Contending with Fibromyalgia

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ABSTRACT

The aim of this study was to obtain a more profound understanding of the inner world of individuals contending with fibromyalgia that might contribute to the development of more effective intervention strategies on various levels. Fibromyalgia is a chronic pain-inducing illness that affects both physical functioning and emotional wellbeing. Society's lack of recognition of the illness and its ramifications make coping with it even harder. The standard medical treatment consists of analgesics, but studies have found that adding individual or group psychological intervention contributes greatly to alleviating the symptoms. A group intervention at a hospital in central Israel that used skills based on the person-in-environment approach provided not only a test of the intervention's efficacy but also a close view of the inner world of people with fibromyalgia. Content analysis of the summaries of the group meetings revealed a great difference between what the individuals felt and what others, including family members, saw or heard. Not being heard may intensify the individual's suffering and prevent recognition by others of the illness. The article describes these issues, which were discussed in the group intervention. This added knowledge may narrow the gap between the inside and the outside and may amplify the voices of individuals contending with fibromyalgia, thus contributing to increased recognition of their condition, more efficacious interventions, and improvement of their quality of life.

KEYWORDS:

fibromyalgia, group therapy, person-in-environment, SUDs Rating Scale, guided imagery, CBT, therapeutic cards

INTRODUCTION

This study set out to obtain a more profound understanding of the inner world of individuals contending with fibromyalgia that might contribute to the development of more efficacious intervention strategies on various levels. Fibromyalgia, also known as muscular rheumatism, is a chronic illness characterized by widespread pain. It causes stiffness of the joints and chronic pain in several bodily areas as well as cognitive disturbances, sleep disruption, anxiety, fatigue, and depression, which negatively affect quality of life (Bernard et al., 2000). Individuals with fibromyalgia also report avoidance and isolation behaviours associated with chronic pain. They often encounter society's lack of recognition of their illness and suffering as well as criticism, because the symptoms are primarily subjective and difficult to diagnose objectively (Chinn et al., 2016; Sarzi-Puttini et al., 2020; van Middendorp et al., 2008). Analgesics are the standard medical treatment, but studies have found that

additional individual or group psychological interventions using strategies such as mindfulness and cognitive behavioural therapy (CBT) help greatly in alleviating symptoms (Anderson & Winkler, 2007; Gómez-de-Regil & Estrella-Castillo, 2020; Grossman et al., 2007; Parra-Delgado & Latorre-Postigo, 2013; Scheidt et al., 2013; Temeloğlu Şen et al., 2019). For example, Grossman et al. (2007) used mindfulness and emotional and social support with 58 women with fibromyalgia. The participants were asked to report, among other variables, the intensity of the pain, how they contended with it, a list of symptoms, and their quality of life. The study included an examination before and immediately after the intervention, as well as a follow-up three years later of 26 participants. The before-and-after examination showed significant improvement in coping with the pain, anxiety level, depression, somatic pain, and quality of life. Even in the follow-up the women reported continued improvement. Parra-Delgado and Latorre-Postigo (2013) found that the use of CBT-based mindfulness alleviated fibromyalgia symptoms. Their six-week intervention involved 33 women with fibromyalgia, randomly assigned to one of two groups. The method was found to be efficacious in alleviating depressive symptoms and (though not significantly) the intensity of the pain. The changes persisted in a three-month follow-up.

Group interventions using various strategies have been found to be very efficacious. Perhaps interacting with a peer group contributes to their efficacy. The work of Anderson and Winkler (2007) supports this assumption. They examined the efficacy of a brief group intervention of 14 meetings, using principles of CBT and emotional support, with 35 individuals with fibromyalgia. Examinations before and after the intervention showed a substantial improvement in symptoms of depression, anxiety, pain, weakness, and fatigue, as compared with the control group.

However, although fibromyalgia also affects and is affected by systems such as the familial (Marcus et al., 2013; Montesó-Curto et al., 2021; Preece & Sandberg, 2005), occupational (Lev & Goldner, 2022; 2005; Palstam et al., 2013; Muller et al., 2017), and medical (Briones-Vozmediano et al., 2013; Colmenares-Roa et al., 2015), most of the interventions are conducted with the individuals themselves and not with these systems.

A study in Spain examined the ramifications for three aspects of life—familial, occupational, and social—as reported by 325 individuals with fibromyalgia (Collado et al., 2014), of whom 96.6% were women and 93% had worked all their lives. Fifty-nine percent of the participants reported fibromyalgia-related difficulties with life partners and 44% reported partial or total dependence on family members in managing their household. Moreover, the family's income dropped, and the fibromyalgia-related expenses grew. At the time of the study, only 45% of the participants were employed and 11% were on sick leave. The study also found low satisfaction with the medical staff, and 26% reported that they belonged to organizations for individuals with fibromyalgia, which they said helped them obtain information about the illness, support, and understanding.

The experience of 35 individuals with fibromyalgia in receiving medical treatment was examined by Durif-Bruckert et al. (2015) using semi-structured interviews. The participants reported that doctors lacked a thorough understanding of the treatments they offered. The sufferers also sometimes felt rejected and humiliated by the





doctors and disappointment with the service provided. In their view, this derived mainly from the doctors' lack of sufficient knowledge about the illness and its symptoms and consequent difficulty in providing suitable treatment. Dissatisfaction, on the part of both the individuals with fibromyalgia and the medical staff, was reported also in the study of Briones-Vozmediano et al. (2013). This study used semi-structured interviews with 12 individuals with fibromyalgia and medical personnel who treated people with fibromyalgia. Both groups expressed dissatisfaction with the amount of time that passed until a precise diagnosis was reached and effective treatment was begun. The individuals with fibromyalgia expressed a desire to receive greater emotional support from the medical staff.

Professional interventions focused only on the individuals with fibromyalgia, no matter how good, may not be sufficient, and help may be needed in additional systems—for example, familial, medical, and occupational. A key approach in social work is the person-in-environment approach (Norton, 2009; Weiss-Gal, 2008), which views the individual within various environments as elements of a single unit that affect each other (Hare, 2004). According to this approach, the ecological system created includes the individual and all the systems within which the individual acts and relates to, including family and various social arrays, and their mutual relations (Johnson & Yanca, 2001; Kondrat, 2013). Social workers are directed to use this approach to achieve interactive and comprehensive observation of the problems of individuals, families, and communities, which are seen as deriving from individual and environmental factors (Karls et al., 2008).

The relevance of the person-in-environment approach in social work in medical settings has been reported by Nilsson et al. (2013). A study conducted among 120 hospital employees in Melbourne, Australia, found that the social worker's role in the hospital accords with this approach. The role is multidimensional, involving intervention at the level of the sick individual and with the family and significant others and enlisting them on additional levels. The scope of that role makes it important to try to link additional levels of intervention, beyond the many important individual interventions mentioned in this study.

The findings in the literature, particularly regarding the efficacy of group interventions in managing the illness and improving the individual's quality of life, and the unmet needs of individuals contending with fibromyalgia that were identified in individual treatment led social workers in the rheumatology institute in a hospital in the centre of Israel to initiate a group intervention using skills of mindfulness, CBT, and guided imagery, in addition to airing and sharing of emotions (van Middendorp et al., 2008). This intervention also enabled close and direct contact with the inner world of individuals with fibromyalgia—their feelings and coping strategies. The current study used content analysis to examine the group's discourse, as journaled by the social workers, in an attempt to discover the main themes that characterize this population. The aim was to try to achieve in-depth understanding of the participants' world and with this knowledge to point the way toward more efficacious professional interventions not only with individuals but also with various systems.

METHODOLOGY

This study of individuals with fibromyalgia took place in the rheumatology institute of a mid-sized hospital in central Israel, in October–November 2021 and included eight weekly group meetings, each lasting 90 minutes. The second and third authors, who are social workers in a hospital, facilitated the meetings. The second author heads the social work service in the hospital and the third author is a senior social worker and team head. Neither of the facilitators had a therapeutic or any other relationship with the group’s participants.

Each meeting included a self-administered measure of distress (using the SUDs Rating Scale), at the start of the meeting and at the end. This measure enabled the participants to examine the effect of participating in the group on their individual stress level. Time was allotted for getting to know each other and for practicing the elements of mindfulness in the group. For example, the participants practiced skills that included creating a safe space, creating a breathing space, and guided imagination. For the 10-minute “creating a safe space” practice, the participants were instructed to think of a real or imagined place that felt safe, quiet, and calm, to try to experience their five senses there, and to report back to the group. Group time was also allotted for an open discussion of the effect of practicing the skills, both within and outside the group, of the illness’s effect on the individuals’ lives, and the coping skills they had developed. The facilitators used such tools as strengths perspective cards, the story of my name exercise, the circles of concern and influence model, the de Bono thinking hats model (de Bono, 2017), Beck’s model for identifying cognitive distortions (Yurica & DiTomasso, 2005), and Merlin cards. In using the “strengths perspective” cards, for example, participants were asked to select a card and present themselves to the group accordingly. One participant chose the “family strength” card and pointed out that she and her family stand by each other. In “the story of my name” exercise, whose goal was to promote greater familiarity among the participants, the facilitators divided them into pairs to share with each other the story of their name; each member of the pair then reported back to the group about their partner. In this way, participants could “hear” their story from a different perspective and examine it from a distance. The de Bono thinking hats model was used to enable the participants to develop awareness of their individual thought patterns in contending with daily life.

THE PARTICIPANTS

The participants constituted a convenience sample of fibromyalgia patients with the following characteristics: diagnosed as having fibromyalgia, ages 40–66, highly motivated and committed to continuous participation in the group, proficiency in Hebrew, and minimal interpersonal skills. Of all the 12 individuals in the group to whom we turned, nine agreed to participate in the study. Table 1 provides basic information about the participants. To maintain confidentiality, each participant was assigned a letter in place of the name.





Participants	Age	Sex	Marital status	Occupational status
A	63	Female	Married +3	Retired
B	65	Female	Widowed +2	Doctor
C	49	Male	Single	Unemployed; receives disability benefit
D	50	Female	Married +3	Undergoing occupational rehabilitation
E	63	Female	Divorced	Unpaid leave
F	43	Female	Divorced +2	At home because of at-risk pregnancy
G	56	Female	Married +3	Unemployed
H	53	Female	Widowed +1	Unemployed; receives disability benefit
I	48	Male	Married +4	Employed as maintenance person

TABLE 1. Personal and occupational details of the participants.

DATA ANALYSIS

The first author, a researcher and social worker with expertise in rehabilitation, conducted content analysis (Creswell, 2014; Hsieh & Shannon, 2005) of the documentation of the group meetings that was written by the two facilitators after each meeting. In the first stage, the summaries were read one after the other. In the second stage, several dominant motifs were identified and will be presented in detail. In the third stage, they were gathered into main themes and named. The validity of the analysis was established by means of investigator triangulation (Carter et al., 2014) by the other two authors. The first author did not know the participants, thus contributing greatly to the study's reliability.

ETHICS

The study was approved by the ethics committee of the hospital in which the group intervention took place. Each participant provided informed written consent for the study's findings to be published.

FINDINGS

This study did not set out to examine the efficacy of the intervention methods (including mindfulness, CBT, and emotional support) used in the group meetings, but because the participants spontaneously addressed these methods, we will describe them briefly. Their remarks can be divided in two: the contribution of the methods in various aspects of their lives and the difficulties of implementing them.

THE CONTRIBUTION OF THE INTERVENTION METHODS

Several times, after the conclusion of the various activities—including practicing guided imagery, focusing on breathing, and relaxation— some of the participants said that the exercises helped them feel calm and less stressed. The objective tests ap-

plied over the course of the meetings confirmed that their stress level decreased following the exercises, which also seemed to help on various emotional levels, as the documentation shows:

[B] shared a childhood memory in [Soviet] Georgia with her family. [She] described a mountainous area covered in snow, which connected her to a feeling of her heart opening up.

[G] said that the guided imagery took her to a trip to Slovakia in which she had participated, and she described a multidimensional picture that connects her to a feeling of ability and capability (G).

The ramifications of the exercises and the new skills that they acquired, on additional levels that are not related to contending with fibromyalgia, were demonstrated by a group member:

[D] shared that today she received bad news regarding a relative and found herself doing an exercise of guided imagery and using it to calm herself. She shared that this was made possible for her thanks to the exercises conducted at the meetings.

However, it is also possible that these experiences, like the participation in a peer group, contributed to the participants on levels that were not planned to be included. For example, the facilitators reported that in one of the meetings, with no prompting, the participants said that coming to the group and meeting others who were contending with the same difficulties and sharing them was of great help. This can also be seen in the documentation regarding C's announcement after the meeting.

[He] posted in the WhatsApp group, including a video clip on the beach in Jaffa, and wrote thanks for the wonderful meeting after which he walked to the beach.

DIFFICULTIES IN IMPLEMENTING INTERVENTION METHODS

Despite the contribution of the new tools, some participants reported difficulty in implementing them, deriving mainly from characteristics of fibromyalgia. Regarding methods that require physical calm to be effective, some reported that their bodily pain, the urgent need to go to the toilet, or noises in the environment, made it difficult to concentrate and relax. Some said that doing the exercises while seated rather than in motion was physically very difficult. These methods may need to be adapted.

However, this study focused mainly on the voices of the participants. Content analysis of the documentation of the meetings showed that their discourse related to the familial, medical, public, and social systems, but also to solutions they had developed to help. We now present their words in accordance with this division.





'MY FAMILY AND ME'

One of the most striking characteristics of the participants was the great divide between what they felt and what they were able to express. This was evident especially in their relations with their family members as a pattern in every aspect of their lives. Some shared that their 'normal' position was to make their family members their top priority, putting their own needs at the bottom. The following documentation offers an example.

D said in the group that she had supported everyone all her life and had become a wreck. However, outwardly she radiates that everything is alright. She also shared that for six years after her fibromyalgia diagnosis she has been waking up at 6 a.m., getting dressed, and preparing sandwiches for the family members so as not to encounter their worried looks.

B, too, shared...the place she was in several years before when her husband [was ill] and she was alone and did not leave his side for even a moment... Although now she is in a different place, freer and knowing how to say it when she needs her children's help, she still [debates] how much to share her pain with her immediate environment and how strong she should appear.

It appears that it is not easy to change the pattern of relationships, even when one decides to do so, and this may even harm the individual's health. For example, participant A decided not to cook for the Sabbath (because of her illness) and suddenly her son called to say that he was coming over, and then she was angry that she had not cooked.

'THE ENVIRONMENT AND ME'

The dominant voice in the group related to their lack of recognition by the establishment and medical personnel: Doctors give them prescriptions that do not help and do not listen to them. The strong feeling was that fibromyalgia receives no public recognition and that they are not recognized as people with rights. This is evident in the documentation of D's words.

She shared the suffering she has experienced since receiving the diagnosis... which took away her power of giving and her power of vitality and left her with a difficult feeling of emptiness and lack of self-esteem...[She] expressed feelings of anger toward the establishment and the health system and the feeling of her invisibility to them....She says they have nothing to offer ['invisible' patients].

The feeling of invisibility expressed by this participant can also be heard in the words of others. C, for example, pointed out that the meetings give him recognition, so important considering the invisibility of the illness to others and the environment's criticism that he experienced. H said that she felt that [the world of] medicine was



not helping her and that she was not visible at all to the doctor. Despite these difficulties, some participants still debated whether and what to share with their environment. Perhaps this derives from society's difficulty in encountering disability, as evident in the words of B, who shared that she still conducted an internal dialogue over how much to share the pain with her immediate environment and how strong to appear. Perhaps because most participants relied only on themselves and rarely shared their suffering with others or sought outside help, they were able to share their personal coping strategies, which we now present.

'I COPE' ON MY OWN

The most common coping method, described or proposed, was 'putting myself in the centre.' This is evident in the words of C and A, in the documentation.

[C] shared that he had decided to look out for himself. For example, he sits in a café in the morning, and he chose a home that serves his social needs. According to him, he has accepted his situation and is learning to put himself in the centre.

[A] described the dramatic change she underwent from a woman lacking in confidence who put everyone around her in the centre to her ability today to also put herself in the centre without negating the values of giving to the other.

This pattern was expressed also in the words of A in another session near the end of the group's meetings.

[A shared] that she wants to...continue doing what is good for her. She shared the *joie de vivre* that she tries to maintain. We talked about the previous meeting, when she succeeded in clarifying...what caused the change from lacking self-confidence to [choosing] to do things that give her joy...And she shared that a week ago she started studying voice development.

And as proof, at the end of the group meetings she burst into an Italian song that received a round of applause from all the group participants.

Another strategy the participants used to ease themselves and reduce their feelings of loneliness was expressed by H, who adopted a stray dog and cat and agreed to participate in the group. Some participants said explicitly that participation in the group marked the beginning of a process of 'looking out for myself first.' The effect of group participation on significant processes of change is evident movingly in D's words, as documented.

[D] spoke about the group as being very meaningful for her and [freeing her] from the bonds that had held her...Thanks to her success in persevering in coming to the group, she dared to accept an invitation from the professional rehabilitation branch and to participate in training of the National Insurance Institute. She is learning that she is able, and this causes her to feel significant.



DISCUSSION

This study aimed to listen closely to the voices of individuals contending with fibromyalgia, voices that usually neither speak nor are heard. But that is not enough, because it is important to try to use this deep understanding to change various aspects of their lives. Therefore, we will try first to understand what the participants were saying and then will propose intervention strategies in keeping with the person-in-environment model (Karls et al., 2008; Norton, 2009; Weiss-Gal, 2008).

The efficacy of the intervention methods used with the participants—including mindfulness, CBT, group work, and emotional support—supports the findings of previous studies (Anderson & Winkler, 2007; Gómez-de-Regil & Estrella-Castillo, 2020; Grossman et al., 2007; Parra-Delgado & Latorre-Postigo, 2013), which examined their effect on the quality of life of individuals with fibromyalgia. In our study, too, the participants reported that they reduced their symptoms and stress and gained a greater sense of wellbeing. One of the variables that influenced them greatly and was mentioned repeatedly was meeting with a group of peers (Anderson & Winkler, 2007). This seems to have had a significant influence on generating changes in the individuals' lives that are important for improving their quality of life.

However, it is also important to listen to the difficulties described in implementing some of these intervention methods so as to adapt them to the illness. Some participants had difficulty in relaxing their body as required, because of intrapersonal or external factors, which influenced their ability to derive the maximum benefit from the intervention. Therefore, it is important to adapt the instructions to individuals' living conditions so that the advantages outweigh the obstacles. Perhaps this limitation led the participants to seek individual alternatives that might help ease their symptoms. Some reported using relaxation means outside the house—walking along the beach, going to cafes, walking pets—but it seems that the most important and significant strategy was the attempt to put oneself in the centre, as opposed to their usual habit.

Analysis of the group discussion enabled a more thorough understanding of the participants' perceptions of their families and their environments. What stood out was their difficulty in sharing their feelings, even with the family members with whom they lived, and their putting their loved ones' wellbeing and needs before their own. Perhaps this lack of sharing, coupled with the medical system's failure to understand their suffering, creates a feeling of invisibility. These findings support those of previous studies (Collado et al., 2014; Durif-Bruckert et al., 2015; Montesó-Curto et al., 2021), which reported fibromyalgia's effect on systems, including the familial, medical, and occupational.

As noted above, most of the medical-therapeutic and psychological or emotional interventions are individual or group interventions with the sick person. Without diminishing their importance, which has been demonstrated by many studies (Anderson & Winkler, 2007; Parra-Delgado & Latorre-Postigo, 2013; Scheidt et al., 2013), the current study suggests improvements, such as adapting techniques and interventions to the characteristics of fibromyalgia. To that end, a deeper understanding is needed of the users' experience, and this may help in adapting them to the individual's needs.

Studies cited in this article have demonstrated that fibromyalgia also affects and is affected by additional systems: familial (Marcus et al., 2013; Montesó-Curto et al., 2021; Preece & Sandberg, 2005); occupational (Lev & Goldner, 2022; Palstam et al., 2013; Muller et al., 2017); and medical (Briones-Vozmediano et al., 2013; Colmenares-Roa et al., 2015). These effects can also be seen in the words of the participants in the current study. They reported their and their families' mutual influence with regard to the illness, the difficulty of functioning at work, and, of course, the relations with the medical system and those who treat them. In light of that, and on the basis of the principles of the person-in-environment approach (Norton, 2009; Weiss-Gal, 2013), it is important to develop varied intervention strategies in these systems too, alongside continuing the person-in-environment intervention with the individual. For example, we propose family support to help family members, too, to accept and understand the illness and its ramifications, but also to cope with its ramifications for them. This intervention may, for example, enable the individuals contending with the illness to feel better understood by their family members and able to involve them more, without hesitating. Helping a family cope with the illness of one of its members may contribute to improving their quality of life and reducing the ramifications for them, as reported in various studies (Collado et al., 2014; Marcus et al., 2013; Montesó-Curto et al., 2021).

In addition, it is possible to develop community or organizational intervention strategies with the medical team in the departments that treat fibromyalgia and also with family doctors, who are often the first link in the treatment chain. As various studies have found, doctors treating fibromyalgia often experience frustration and helplessness vis-à-vis the illness, and this certainly does not help them or their patients (Briones-Vozmediano, 2013; Durif-Bruckert, 2015). Direct interventions with the medical staff and raising their awareness of the illness, may help them attain a more thorough understanding of the illness and especially of its emotional, psychological, and behavioural ramifications. This process may contribute to greater empathy and understanding, may help create a closer and more effective therapeutic relationship for both sides, and may reduce the feelings of helplessness and frustration. Similarly, mechanisms can be developed for raising public awareness of the ramifications of fibromyalgia for the individual's functioning, for example, in the workplace. As this study reported, some individuals with fibromyalgia have difficulty in this area, often because of the lack of allowances for their illness (Collado, 2014). Greater awareness of the topic may make employers more understanding and sensitive to the needs of individuals with fibromyalgia and thus increase the percentage of employed individuals among them, which may contribute to their quality of life. It is very likely that these processes on various levels will contribute to making the voices of fibromyalgia sufferers heard and that their feeling of invisibility in their environment will decrease.

CONCLUSION

This study set out to hear the voices of people contending with fibromyalgia, by means of a therapeutic group that used various tools for coping with the illness's ramifications. Although it was not the main aim, the participants reported that they





benefited greatly from the intervention, but they also pointed out obstacles to using the tools on their own.

The study enabled us to propose a broader, multi-dimensional intervention model, based on the principles of the person-in-environment approach, to try to create change that goes beyond the individual to additional systems that affect the individual's functioning. Implementing this model may benefit the individuals with fibromyalgia, their family members, medical system representatives, the occupational system, and others.

Nevertheless, this study is not without limitations. The participants are a small group who chose to participate. This population may have unique characteristics. The population that is not represented in this study may cope better, or worse, with the illness, and may have different, and possibly more effective, coping mechanisms that it is important to study. Also, the group was facilitated by two social workers in the hospital where all the participants are treated, although there was no therapeutic or other relationship outside the group between the social workers and the study's participants. This may have influenced the topics that arose and the voices that were heard, which were also the basis for the abovementioned proposed intervention. Therefore, we recommend testing the hypotheses that arose from the participants' voices in a broader study in which the participants are anonymous to the researchers.

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