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Problems and Solutions for Patients with Fibromyalgia: Building New Helping Relationships

Running head: Problems and Solutions for Patients with Fibromyalgia

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Conflict of interest

No conflict of interest has been declared by the authors.

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Abstract

Aim

To identify the main biological, psychological and sociological problems and potential solutions for patients diagnosed with fibromyalgia by use of Group Problem-Solving Therapy.

Background

Group Problem-Solving Therapy is a technique for identifying and solving problems, increasing assertiveness, self-esteem and eliminating negative thoughts.

Design

Qualitative phenomenological interpretive design: Group Problem-Solving Therapy sessions conducted with patients suffering fibromyalgia were studied; participants recruited via the Rheumatology Department at a general hospital and associations in Catalonia, Spain with sessions conducted in nearby university setting.

Methods

The study included 44 people diagnosed with fibromyalgia (43 female, 1 male) from 6 Group Problem-Solving Therapy sessions. Data collected from March-June 2013.

A total of 24 sessions were audio recorded, all with prior informed consent. Data were transcribed and then analysed in accordance with established methods of inductive thematic analysis, via a process of reduction to manage and classify data.

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Findings

Five themes were identified: (1) Current problems are often related to historic trauma; (2) There are no 'one size fits all' solutions; (3) Fibromyalgia is life-changing; (4) Fibromyalgia is widely misunderstood; (5) Significant impacts on physical, psychological and social are described.

Conclusion

The majority of patients' problems were associated with their previous history and the onset of fibromyalgia; which may be related to trauma in adolescence, early adulthood or later. The solutions provided during the groups appeared to be accepted by the participants.

These findings can improve the self-management of fibromyalgia patients by helping to enhance adaptive behaviours and incorporating the female gender approach.

Keywords: fibromyalgia; problem solving therapy; difficulties; solutions; qualitative study; interpersonal relations; trauma; phenomenology; nursing.

Summary statement

Why is this research needed?

- The evidence suggests that patients who follow Group Problem-Solving Therapy (GPST) express feelings of healthy anger, which can mitigate the effects of fibromyalgia.
- There is limited research about the effects of GPST in FM and care for people fibromyalgia has often been found to be of poor quality.

What are the key findings?

- GPST improves understanding of the difficulties and solutions identified by patients, increasing the salience of the association between female gender perspective and fibromyalgia.
- This research further establishes the importance of patients and nurses working together to identify and address the main problems affecting those diagnosed with fibromyalgia.
- GPST enhances perceived control for patients; contributing to the development of skills to fight the disease and its symptoms.

How should the findings be used to influence policy/practice/research/education?

- Reports on a standardized intervention for fibromyalgia patients, which can be used by nursing staff to provide their patients with tools to help manage their disease.
- There is a need for more research with patients diagnosed with fibromyalgia, to further capture their views and experiences, so as to improve care.
- Healthcare policies need to include care models such as GPST in fibromyalgia, so as to encourage healthy behaviours and techniques for self-care and coping.

Introduction

Fibromyalgia (FM) is pain in the muscles, ligaments, tendons and fibrous parts of the body. It mainly affects non-articular muscles. Its main features are widespread pain and exaggerated sensitivity at multiple points, known as 'tender points' or 'trigger points' (Galindo 2004). It occurs in 2-4% of the population (Sumpton & Moulin 2014) and 90% of those diagnosed are women. The most common age of onset is between 30-60 years, but it can occur at any age including adolescence and old age. It is recognized as an increasingly important health problem (García & Alda 2004) and it is a significant

economic burden on society (García & Alda 2004, Winkelman *et al.* 2011), responsible for up to 75% of the indirect costs of lost productivity.

The treatment of FM is controversial and complex, particularly due to the inter-relatedness of depression and chronic pain in the condition (Catala & Aliaga, 2003). Recommendations as to how to address this issue differ between countries; with varying combinations of tricyclic antidepressants, selective serotonin reuptake inhibitors, wide-ranging analgesia, psychological interventions (e.g. cognitive behaviour therapy) and graduated aerobic exercise being advocated (e.g. Carville *et al.* 2008, Winkelman *et al.* 2012, Fizcharles *et al.* 2013). Whilst pharmacological treatments have aimed to minimise the impact of chronic pain in FM, increasingly psychological interventions focus on strategies to incorporate into daily life; so as to help people to accept chronic pain and teach them to live as normal a life as possible despite the pain (Comeche & Vallejo, 2012).

The most effective strategy appears to be to combine pharmacological and nonpharmacological interventions (Hassett & Williams 2011, Ablin *et al.* 2013, Lee *et al.* 2014). Interdisciplinary treatment programs are suggested to have led to improvements in subjective pain (Hassett & Williams 2011, Sarzi-Puttini *et al.* 2011).

Background

Given the difficulties experienced by women with FM and sufferers' low quality of life, we believed that it would be helpful to develop and implement a program using group cognitive-behavioural therapy techniques; i.e. Group Problem-Solving Therapy (GPST). This is a group approach that brings together techniques for identifying and solving problems, increasing assertiveness and self-esteem and eliminating negative thoughts. The GPST was therapeutic intervention and research tool with a phenomenological approach with content analysis (Grbich 2007).

GPST, based on Problem Solving Therapy (PST), is a non-specialized therapy, relatively short and easy to learn that can be used at any level of health care setting to care for patients and families (Ferre et al, 2008). After use, patients with FM appear to obtain an improvement in both somatic and psychological symptoms (Menga *et al.*, 2014, Kashikar-Zuck *et al.*, 2013, Thieme & Turk, 2012).

The intervention program consisted of four sessions: three sessions at one-week intervals and a fourth session at one month following the third session. During the first session, the participants identified their main problems. They were suffering at the physical, psychological, or social level. They also explored their problems to know when they happened, where they occurred and who was involved. The second session consisted of finding potential solutions to these problems. The solutions could be put forward by the person themselves or by other members of the group. In the third session, the implementation of possible solutions was designed and in the fourth sessions, the reported results of implementation at home were evaluated. Many times the identified solutions did not completely solve the identified problems. However, improved coping and management of emotions to face problems that often had no solution was reported (Montesó-Curto *et al.* 2015).

Chronic pain involves a set of physiological, emotional, cognitive and behavioural issues involved in pain perception. One of the characteristics of chronic pain is its resistance to conventional analgesia. Therefore, most psychological therapies do not directly aim to eliminate pain; rather, they focus on getting patients to accept the suffering associated with a chronic disorder and learn a range of strategies to help them maintain as normal a life as possible despite the pain (Comeche & Vallejo 2012).

GPST is not a specialized therapy; it is a relatively brief intervention that is easy to learn and to implement at any level of care (Ferré *et al.* 2008). Zurilla and Goldfried in 1971 developed a stepped problem-solving strategy for finding new solutions to a given situation or problem, defining a problem as the failure to find an effective response to a situation or event. GPST was as effective as other psychosocial therapies and medication treatments and significantly more effective than other

supportive treatment (Bell & D’Zurilla 2009). GPST interventions conducted by nurses have been highly successful in treating depression (Mynors-Wallis *et al.* 1995, Vázquez 2002, Bell & D’Zurilla 2009, Ferré-Grau *et al.* 2014). They have also proved to be useful in a wide range of stressful situations, although they are most commonly used to cope with physical or psychological illness; i.e. situations where there is a perceived impact on interpersonal relationships, personal status and/or situations involving important decision making. Anxiety and depression (Pérez-Pareja *et al.* 2004, Montesó-Curto *et al.* 2010, Shipley 2010, Aguglia *et al.* 2011, Caro & Winter 2011, discomfort (Valls 2007), overload of family/work responsibilities, low family support, significant difficulties in childhood (Montesó-Curto *et al.* 2010) and gender violence are all more prevalent in patients with fibromyalgia (Sallinen *et al.* 2010). It is therefore also important to seek to increase patients’ skills for coping with such situations (Comeche & Vallejo 2012). GPST appears to help patients to express feelings of healthy anger, which can mitigate the effects of fibromyalgia (Van Middendorp *et al.* 2010).

The study

Aims

To identify the main biological, psychological and sociological problems and solutions for patients diagnosed with FM by use of GPST.

Design and participants

This qualitative study was part of larger randomized controlled trial on the perception of discomfort and psychosocial difficulties in patients diagnosed with FM and predominant neck pain (Montesó-Curto *et al.*, 2015). In this trial, the participants were recruited from individuals attending a rheumatology department at a general hospital and via three FM associations. Male or female patients were eligible for the trial, if they had been diagnosed with FM and were willing and able to participate in a 2-hour discussion. Exclusion criteria were the presence of a cognitive impairment,

such as Alzheimer's Disease, an uncontrolled psychiatric disorder or hearing difficulties. Group Problem-Solving Therapy (GPST) took place in the local university setting between July 2012 and December 2013. The 44 patients of the trial that were assigned to the group that was administered GPST were randomly divided into six groups. For the present article, data were collected from the different sessions of GPST and a phenomenological approach of patients' speech was made and drew on the socio-anthropological symbolic interaction perspective set forth by Blumer (1999).

Phenomenology in this context is defined as a methodological approach that captures the 'experience' of people (i.e. with FM; which explores and identifies subjective experience, how it is perceived and what it means for individuals (Burns & Grove, 2004). In this way, phenomenology aims to describe and explore understandings of a particular phenomenon (Streubert & Carpenter 1999).

Ethical considerations

The Ethics Committee of Joan XXIII Hospital in Tarragona (Catalonia, Spain) gave its approval for the trial in February 2013 (40P/2012). Since all the participants had given informed consent to participate in the trial, the 44 participants to the GPST section of the study received a further briefing on the GPST sessions and signed the Participant Information and Consent Form.

Data collection

Each group was led by two professors from the School of Nursing trained in problem-solving therapy. One of the professors took audio recordings and notes while the groups explained their experiences to the other professor. A total of 24 sessions were recorded, all with prior consent. The GPST intervention consisted of four two-hour sessions. The first three sessions occurred at weekly intervals and the fourth session took place one month later. During the first session, the participants identified the main problems they had at the physical, psychological and social level. They also explained when the problems occurred and who was involved. The second session consisted of

finding solutions to these problems. The main problem was identified first, if it had not been well defined in the previous phase and a minimum of 10 solutions were identified for each problem. The identified solutions were implemented during the third session. The solutions could be put forward by the person talking about the problem, the other members of the group, or the two people leading the sessions. The solutions provided often could not solve the problem completely; the aim was to make participants aware that the difficulties that arise in people's lives can be assessed differently and addressed more effectively, as can the negative feelings derived from these experiences, such as anger and frustration. Finally, the effectiveness of the GPST was evaluated in the fourth session. An assessment was made of the effectiveness of the solution provided or the extent to which it reduced the negative experience. The main aim was not to solve all the patients' problems, but for them to see that almost all problems may have a solution (Montesó *et al.* 2015).

Data analysis

Data were transcribed and analysed in accordance with established methods of inductive thematic analysis, via a process of reduction to manage and classify data (Hsieh & Shannon 2005, Milne & Oberle 2005). Content analysis was used to analyse the information. Conventional content analysis is generally used with a study design whose aim is to describe a phenomenon, in this case to identify the main problems affecting patients diagnosed with FM (Hsieh & Shannon 2005). This type of design is often appropriate when the research literature on a phenomenon is limited. The data were transcribed verbatim after GPST sessions. Members of the research team repeatedly read the transcripts to get an initial awareness. They then generated codes and grouped them into categories. These were further agreed on by other researchers in the team. These categories were then grouped into themes with consensus of the whole group. Thus, the researchers avoided using a priori categories. Rather, categories were encouraged to emerge from the data; i.e. by researchers immersing themselves in the data so as to allow new ideas to emerge (Kondracki & Wellman 2002); also described as inductive category development (Hsieh & Shannon 2005). We classified into

themes those problems that were prioritized by participants; i.e. the physical, psychological and social impacts (problems and solutions; Table 2).

Rigor

The number of participants was considered suitable for a phenomenological study since it involved a large volume of in-depth data (Streubert & Carpenter 1999). It was considered that there was saturation when the data provided, instead of providing new explanatory elements, only increased the volume of them. This is like the concept known as "theoretical saturation" (Glaser & Straus 1967). We considered this achieved in the GPST study, if in the second and third session there were problems or solutions that were not identified in the previous sessions. If so, they were also included for later analysis.

To enhance the rigor of data analysis, all audio-recorded data were transcribed and then independently cross-checked for accuracy by five researchers (PM, MM, MTC, SR, ALL). The transcriptions were then read repeatedly by three members of the research team (MLP, MGM, LSC). A content analysis of the transcripts was then independently conducted by the first (PM) and second author (MGM) with highlighting of words, phrases and paragraphs that stood out in the transcripts. After this process, a meeting with the seven other researchers allowed to reach a consensus on the final encoding, which was subsequently incorporated into the transcripts. Meaning units were then grouped together and organized into themes (Saks & Allsop 2007).

Findings

The general overview of the profile of the participants obtained in the trial study indicated that: (1) the average age of the participants was 61.1 years SD 8.2 years; (2) with 97.7% (42) of the sample female; (3) 46.5% were retired or drawing some sort of pension and only 7.0% were active workers; (4) mean number of years between the onset of symptoms and diagnosis of the disease was 9.8 (SD 8.3) years and the mean number of years the patients had lived with the diagnosis was 11.6 (SD 7.4)

years; (5) mean score for satisfaction with the healthcare system was 7.1 (SD 3.1); for satisfaction with medication was 5.2 (SD 2.6); and for satisfaction with nonpharmacological therapies, it was 7.2 (SD 2.9) (Table 1). The satisfaction scale was a Likert scale where the minimum satisfaction was 0 and the maximum 10.

Regarding the qualitative analysis of this study: five themes were identified through the data analysis (Table 2). These themes consisted of: (1) Current problems are often related to historic trauma; (2) There are no 'one size fits all' solutions; (3) FM is life-changing; (4) FM is widely misunderstood; (5) Significant impacts on physical, psychological and social are described.

Theme 1: Current problems are often related to historic trauma or chronic stress

When exploring their current problems, patients with FM usually refer to the past, identifying events or factors which they believe caused the disease. Their stories suggest that 'suffering', 'anger' or perceived 'stress' can take two forms: an acute episode of serious stress which is perceived as very stressful, or more chronic, persistent stress.

In most cases patients relate the onset of FM to trauma during childhood, adolescence, early adulthood or later. Intimate partner violence, childhood abuse, the sudden loss of loved ones (e.g. in traffic accidents) and complications during childbirth are all common in people with FM.

In other cases the onset of FM is related to more recent negative experiences. The traditional role of women is important in understanding FM; women are expected to multitask from childhood, including doing the housework and caring for a family and for many of the women in our study this is not a positive experience. They believe that for them the FM appears after a series of events that the person cannot stand.

Theme 2: There are no 'one size fits all' solutions

Various solutions were proposed for reducing pain. Not every solution works for all women, although most could be used as a guide. Each woman should be treated individually. Whilst one woman may feel better taking Voltaren another may prefer Tramadol and some women do not benefit from any pain medication. In terms of non-pharmacological treatments, some FM sufferers feel better after swimming and massages are generally beneficial. There are also people who have taken tramazolin and derivatives of morphine for many years and now they do not take it.

Theme 3: FM is life-changing

There is a before and after in your life when the disease appears. Sufferers felt that the disease had changed their lives and they were not the person before; some tried to adapt and accept the changes the disease forces on them. Some have had to leave their offices and their work. In the workplace they say they want you to get to everything but the person cannot do it.

Theme 4: FM is widely misunderstood

Sufferers felt misunderstood by the society, friends and partner/ family, health system: doctors, specialists and friends. In the health system, there are some professionals who begin to understand the disease but others do not and people feel misunderstood. They believe that it is a disease that has little information available and that if all the professionals with more training available, things would change. They argue that some well-trained specialists and general practitioners do understand them perfectly.

Theme 5: Significant impacts on physical, psychological and social are described

The impact of the disease affects the physical, psychological and social dimensions of life. In the physical dimension, the manifestations that most concern them are the following: ongoing pain, fatigue or overload, difficulty with daily activities, memory problems, difficulty in mobility and allergies. In the psychological dimension it appears that depression, anxiety and rage dominate; and in the social dimension, loneliness, lack of support from a partner and abuse stand out.

Discussion

The results suggest that the impact of FM in people's lives is considerable and also that GPST had distinguished the main problem situations in the lives of people with FM; providing solutions to improve their coping, their recovery and improvement in symptoms. The type of relationship counselling that we implemented in the GPST was like that described elsewhere in the literature in studies on cognitive-behavioural therapy and that improved functional capacity and pain. (e.g. Kashikar-Zuck *et al.* 2011, Botella *et al.* 2013, Sumpton & Moulin 2014). We also have observed that the coping strategies or solutions (as we refer to in the results) can be incorporated in the management of the disease for both clinicians and people themselves; since it has been seen that this disease requires a multi-faceted approach where self-management of symptoms is the key (Sumpton & Moulin 2014).

As our participants had all been living with FM for considerable time, early and effective intervention is important because symptoms tend to persist unless ameliorated. This makes cognitive behavioural therapy approaches such as GPST, an important tool for improving mood and daily functioning (Joffe *et al.* 2014, Kashikar-Zuck *et al.* 2013).

When we explored the current problems, they used to go back to the past, identifying elements that related to the origin of the disease. As shown by Hallberg and Carlsson (1998), there are numerous examples of early loss, traumatic life history, high degree of responsibility early in life and over-compensatory perseverance. There is an association between birth trauma', adversity and the development of chronic pain in later life (Afari *et al.* 2014, Low & Schweinhardt 2012). Among these traumas, physical and/or mental trauma due to abuse and violence also appears as exacerbating the impact of FM, leading to a loss of self-esteem. However, this remains mostly hidden in our society. Also, intense pain was related with depression and anxiety (cf. Sallinen *et al.* 2010). For this reason, the authors recommend during the treatment of FM that healthcare professionals remain sensitive to detection and monitoring of gender violence; as well as awareness of the possible comorbidity of depression and anxiety in FM (see also Özer *et al.* 2014).

The most frequently discussed symptom was pain. The participants pointed out that long bouts of engaging in one activity could significantly worsen pain the day after (cf. Arnold *et al.* 2008). The symptoms found and the impact of FM were similar to reports in other qualitative studies (i.e. Cunningham & Jillings 2006, Hallberg & Carlsson 1998, Sturge-Jacobs 2002). However, recent studies have shown that lower levels of physical inactivity are associated with lower pain, fatigue and impact of disease (Segura-Jiménez *et al.* 2017).

The severity and unpredictability of the symptoms made it difficult to function at work, or in social or leisure activities and that the lack of understanding or general acceptance of FM contributed to social withdrawal and isolation (Arnold *et al.* 2008). Like Arnold *et al.* (2008) in our study pain is an important element, but there is a restrictive effect of the disease that prevents persons with FM from performing multiple activities. There are also elements of loss of identity and perceived incomprehension and loneliness, so that the negative impact of the disease is evident in the lives of patients (Wuytack & Miller 2011). Another important concern is memory loss. According to Seo *et al.* (2012), the memory deficit in patients with FM can be attributed to the deficiencies in the neuronal

activation of the frontoparietal red memory and can be as much a contributor as the depression and the anxiety associated to the pain. Satisfaction with non-pharmacological treatments is higher in our study. These results agree with evidence on the effectiveness of medicinal plants or natural products in improving symptoms compared to the use of a drug or placebo (de Souza *et al.* 2013). There is also a spontaneous improvement of pain in FM and a shorter need for medication over time (Pöyhiä *et al.* 2001)

What this paper brings to the debate are the solutions to the problems perceived by the group – the result of reflecting on their experience using GPST – and the importance of emotions in the management of symptoms and of asking for help and of not wanting to do it all alone.

Changing thoughts relating to fear, anxiety and avoidance of activity is important in FM, because if such thoughts remain unchanged they help to sustain the experience of pain (Torres *et al.* 2013).

Consequently, an intervention targeting thoughts and emotions would appear to be effective. Our study followed a similar approach to others which have demonstrated that a change in the focus of activities and beliefs about the disease could reduce symptoms and improve pain tolerance and functional status (Friedberg *et al.* 2012, Thieme & Turk 2012). According to Velasco *et al.* (2006), patients in their sample spoke of difficulties in fulfilling the traditional female gender role. Very high limits are imposed on the labour, domestic and emotional tasks that they have to fulfill due to female gender enculturation in traditional Spanish society. They believe that the tasks have to be performed by them and perfectly, so they do not ask for help from the partner. Several studies have analyzed female gender identity and its association with FM (Valls 2007, Briones-Vozmediano *et al.* 2016).

Conclusions

By using GPST, this study has developed a new analytical approach to perceived difficulties in FM; i.e. from the perspective of the patient. Relating the triggers of FM with previous traumas, or with work overload that women relate to domestic multitasking, suggests an explanation as to why the same treatments do not achieve similar outcomes for all sufferers of FM.

We also highlight that FM changes lives, particularly in the feeling of being misunderstood. This misunderstanding is reduced by the detailed analysis GPST provides of the physical, psychological and social impact FM causes in people's lives. This last point is important, since GPST includes identification of both problems and the solutions and can thus be incorporated into the interventions of nursing care. The GPST approach leads to a better understanding of the disease. The results can be used as a reference for nursing clinical practice and as a model for developing therapeutic relationships with people with FM, to assist them in social interactions and daily life. Experienced patients can be immensely helpful in this process. The results of this study can be used to draw up a standardisable intervention for FM patients which can be used by nursing staff to improve care. The introduction of a female gender perspective to the analysis of negative experiences can improve understanding of the disease and help to deconstruct the traditional family model found in some societies.

Limitations

Despite all patients being diagnosed with FM, most of the participants were women. The findings, therefore, may not represent the perspective of the male population.

Also, the fact that the participants lived mainly in a semi-urban environment of an area of Spain (but with an important rural environment in its surroundings) and that the average age was high, so that the experiences of the disease may be perceived in a different way to the one that could be perceived in a more urban environment and with a younger population needs to be noted.

Another limitation is in the way of conducting the groups. Although all the nurses were trained to unified criteria for conducting the GPST, the fact that they had different areas of professional expertise could influence group dynamics/relationships.

It was also observed that there were groups that were more proactive than others in the detection and management of solutions. Since, in some groups, there were more participants who were members of a local FM Association; this may have influenced these groups. However, it is noteworthy that in some other groups where members of the association were present, they did not dominate discussions. Therefore, it seems more likely that any influencing effect could be explained by the presence of people who had had the disease for a long time and who had achieved a greater management of its impacts; i.e. that FM experience is the key factor.

Author contributions

All authors have agreed on the final version and meet at least one of the following criteria

[recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

References

- Ablin, J., Fitzcharles, M.A., Buskila, D., Shir, Y., Sommer, C., & Hauser, W. (2013). Treatment of fibromyalgia syndrome: Recommendations of recent evidence-based interdisciplinary guidelines with special emphasis on complementary and alternative therapies. *Evidence-Based Complementary and Alternative Medicine*, 485272. doi: 10.1155/2013/485272
- Ablin, J.N., & Buskila, D. (2014). Predicting fibromyalgia, a narrative review: Are we better than fools and children?. *European Journal of Pain*, 18(8), 1060-1066 doi: 10.1002/j.1532-2149.2014.00481.x.
- Afari N., Ahumada S.M., Wright L.J., Mostoufi S., Golnari G., Reis V., Cuneo J.G. (2014). Psychological trauma and functional somatic syndromes: a systematic review and meta-analysis. *Psychosomatic Medicine*, 76(1), 2–11.
- Aguglia A., Salvi V., Maina G., Rossetto I., & Aguglia E. (2011). Fibromyalgia syndrome and depressive symptoms: comorbidity and clinical correlates. *Journal of Affective Disorders*, 128 (3), 262–266. doi: 10.1016/j.jad.2010.07.004
- Arnold L.M., Crofford L.J., Mease P.J., Burgess S.M., Palmer S.C., Abetz L., & Martin S.A. (2008). Patient perspectives on the impact of fibromyalgia. *Patient Education and Counselling*, 73(1), 114–120. doi:10.1016/j.pec.2008.06.005
- Bell A.C., & D’Zurilla, T.J. (2009). Problem-solving therapy for depression: A meta-analysis. *Clinical Psychology Review*, 29, 48–353. doi: 10.1016/j.cpr.2009.02.003
- Blumer H. (1999) *Symbolic Interactionism: Perspective and method*. Barcelona: Masson.
- Botella C., Garcia-Palacios A., Vizcaíno Y., Herrero R., Baños R. M., & Belmonte M. A. (2013). Virtual reality in the treatment of fibromyalgia: a pilot study. *Cyberpsychology, Behavior and Social Networking*, 16(3), 215–23. 10.1089/cyber.2012.1572

Briones-Vozmediano E., Vives-Cases C., & Goicolea I. (2016). "I'm not the woman I was": Women's perceptions of the effects of fibromyalgia on private life. *Health Care for Women International*, 37(8), 836-854. doi:10.1080/07399332.2016.1178265

Burns N., & Grove S. (2004). *Nursing research (3rd ed)*. Madrid: Elsevier.

Caro X. J., & Winter E. F. (2011). EEG biofeedback treatment improves certain attention and somatic symptoms in fibromyalgia: A pilot study. *Applied Psychophysiology Biofeedback*, 36(3), 193–200. doi: 10.1007/s10484-011-9159-9.

Carville, S.F., Arendt-Nielsen, L., Bliddal, H., Blotman, F., Branco, J.C., Buskila, D., ... Choy, E.H.; (2008). EULAR evidence-based recommendations for the management of fibromyalgia syndrome. *Annals of the Rheumatic Diseases*, 67(4), 536-41. doi:

10.1136/ard.2007.071522

Comeche M. I., & Vallejo M. A. (2012). Dolor crónico. [Chronic pain]. In M. A. Vallejo, & M. I. Comeche (Eds.), *Manual de terapia de conducta. Tomo II*. Dykinson: Madrid.

Cunningham, M.M. & Jillings, C. (2006). Individuals' descriptions of living with fibromyalgia. *Clinical Nursing Research*, 15(4), 258–273. doi:10.1177/1054773806291853

de Souza, S., Desantana, J.M., Nampo, F.K., Ribeiro, E.A., da Silva, D.L., Araújo-Júnior, J.X., da Silva, J.R., Bonjardim, L.R., de Souza, A.A., Quintans-Júnior, L.J.(2013). Efficacy and safety of medicinal plants or related natural products for fibromyalgia: a systematic review. *Evidence-Based Complementary and Alternative Medicine*. 2013, 149468. doi: 10.1155/2013/149468.

D'Zurilla, T. J., & Goldfried, M.R. (1971). Problem solving and behavior modification. *Journal of Abnormal Psychology*, 78 (1),107–126.

Ferré, C., Rodero, V., Vives, C., & Buera, D. (2008), *The world of the family career*. Tarragona: Silva Editorial.

Ferré-Grau, C., Sevilla-Casado, M., Lleixá-Fortuño, M., Aparicio-Casals, M. R., Cid-Buera, D., Roderó-Sánchez, V. & Vives-Relats, C. (2014) Effectiveness of problem-solving technique in caring for family caregivers: a clinical trial study in an urban area of Catalonia (Spain). *Journal of Clinical Nursing*, 23(1-2), 288–95. doi: 10.1111/jocn.12485.

Fitzcharles, M.A., Ste-Marie, P.A., Goldenberg, D.L., Pereira, J.X., Abbey, S., Choinière, M., Ko, G., ... Shir, Y. National Fibromyalgia Guideline Advisory Panel. (2013). 2012 Canadian Guidelines for the diagnosis and management of fibromyalgia syndrome: executive summary. *Pain Research and Management*, 18(3):119-26. PMID:

PMC3673928

Friedberg, F., Williams, D.A., & Collinge, W. (2012). Lifestyle-oriented non-pharmacological treatments for fibromyalgia: a clinical overview and applications with home-based technologies. *Journal of pain research*, 5, 425–35. doi: 10.2147/JPR.S35199

Galindo, C. (2004) Fibromyalgia. *Dolor*, 19, 177-187.

García, J., & Alda, M. (2004). La vivencia de la sexualidad en pacientes con fibromialgia: un estudio cualitativo. [The experience of sexuality in patients with fibromyalgia : a qualitative study]. *Archivos de Psiquiatria*, 67(3), 153-155.

Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine Publishing Company.

Grbich, C. (2007). *Qualitative data analysis. An introduction*. Thousand Oaks, California: Sage.

Hallberg, L.R.-M., Carlsson, S.G. (1998). Psychosocial Vulnerability and Maintaining Forces Related to Fibromyalgia: In-Depth Interviews with twenty-two Female Patients. *Scandinavian Journal of Caring Sciences*, 12(2), 95–103. doi:10.1080/02839319850163020

Hassett, A.L., & Williams, D.A. (2011) Non-pharmacological treatment of chronic widespread musculoskeletal pain. *Best Practice & Research Clinical Rheumatology*, 25(2), 299–309. doi: 10.1016/j.berh.2011.01.005

Hsieh, H.F., & Shannon, S. E. (2005) Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. doi:10.1177/1049732305276687

Joffe, N. E., Lynch-Jordan, A., Ting, T. V, Arnold, L. M., Hashkes, P. J., Lovell, D. J., Passo M.H., ... Kashikar-Zuck S. (2013), The utility of the PedsQL Rheumatology Module as an outcome measure in juvenile fibromyalgia. *Arthritis Care & Research*, 65(11), 1820–1827. doi: 10.1002/acr.22045

Kashikar-Zuck, S., Sil S., Lynch-Jordan, A. M., Ting T. V, Peugh J., Schikler K. N, ...Lovell, D.J. (2013). Changes in pain coping, catastrophizing and coping efficacy after cognitive-behavioral therapy in children and adolescents with juvenile fibromyalgia. *The Journal of Pain*, 14(5), 492–501. doi: 10.1016/j.jpain.2012.12.019

Kondracki, N. L., & Wellman, N. S. (2002). Content analysis: Review of methods and their applications in nutrition education. *Journal of Nutrition Education and Behavior*, 34, 224-230.

Lee J., Ellis B., Price C., & Baranowski A.P. (2014) Chronic widespread pain, including fibromyalgia: A pathway for care developed by the british pain society. *British journal of anaesthesia*, 111(1), 16–24. Doi: 10.1093/bja/aet351.

Low, L.A., & Schweinhardt, P. (2012). Early life adversity as a risk factor for fibromyalgia in later life. *Pain Research and Treatment* 2012, 140832. doi: 10.1155/2012/140832

Milne, J., & Oberle, K. (2005) Enhancing rigor in qualitative description: a case study. *Journal of Wound Ostomy & Continence Nursing*, 32(6), 413-20. PMID: 16301909 [PubMed - indexed for MEDLINE]

Menga, G., Ing S, Khan, O, Dupre, B., Dornelles, A.C., Alarakhia, A., ... Quinet R. (2014). Fibromyalgia: can online cognitive behavioral therapy help?. *The Ochsner Journal*, 14(3), 343-9.

Mynors-Wallis, L. M., Gath, D. H., Lloyd-Thomas, A. R., & Tomlinson, D. (1995). Randomized controlled trial comparing problem solving treatment with amitriptyline and placebo for major depression in primary care. *British Medical Journal*, 310(6977), 441–445. doi: 10.1136/bmj.310.6977.441

Montesó, M. P., Ferré, C., & Martínez, V. (2010) [Fibromyalgia: beyond the depression]. *Revista de enfermería*, 33(9), 20–26. PMID: 21090133

Montesó-Curto, P., García-Martínez, M., Gómez-Martínez, C., Ferré-Almo, S., Panisello-Chavarria, M. L., Romaguera, ... S. Ferré-Grau C. (2015). Effectiveness of Three Types of Interventions in Patients with Fibromyalgia in a Region of Southern Catalonia. *Pain Management Nursing*, 16(5), 642–652. doi: 10.1016/j.pmn.2015.01.006

Özer, Ü. , Selimoğlu, E. Badur, E. Uygun, E., & Karşıdağ, Ç. (2014). Relationship of domestic physical violence and severity of pain, depression and anxiety levels in fibromyalgia cases. *Nobel Medicus*, 11(1), 27-32

Pérez-Pareja, J., Borrás, C., Palmer, A., Sesé, A., Molina, F., & Gonzalvo, J. (2004). Anxiety and depression are some of the most frequent symptoms diagnosed by fibromyalgia patients. *Psicothema* 16(3), 415–420. <http://www.psicothema.com/psicothema.asp?id=3012>

Pöyhiä, R., Da Costa, D., & Fitzcharles, M.A. (2001). Pain and pain relief in fibromyalgia patients followed for three years. *Arthritis Care & Research*. 45(4), 355-61

Saks, M., & Allsop, J. (2007) *Researching Health: Qualitative, Quantitative and Mixed Methods*. London: Sage Publications,.

Sallinen, M., Kukkurainen, M.L., Peltokallio, L., & Mikkelsen, M. (2010). Women's narratives on experiences of work ability in fibromyalgia. *Musculoskeletal Care* 8 (1), 18–26.

Sarzi-Puttini, P., Atzeni, F., Salaffi, F., Cazzola, M., Benucci, M. & Mease, P.J. (2011) Multidisciplinary approach to fibromyalgia: What is the teaching?. *Best Practice and Research: Clinical Rheumatology*, 25(2), 311–319. doi: 10.1016/j.berh.2011.03.001

Shiple, M. (2010). Chronic widespread pain and fibromyalgia syndrome. *Medicine*, 38 (4), 202–204. doi: 10.1016/j.mpmed.2014.02.009

Streubert, H., & Carpenter, D. (1999) *Qualitative research in nursing: Advancing the humanistic imperative*. J.B. Philadelphia: Lippincott.

Sturge-Jacobs, M. (2002) The experience of living with fibromyalgia: confronting an invisible disability. *Research and theory for nursing practice*, 16(1), 19–31. doi.org/10.1891/rtnp.16.1.19.52994

Sumpton, J.E., & Moulin, D.E. (2014) Fibromyalgia. *Handbook of Clinical Neurology*, 119, 513–27. doi:10.1016/B978-0-7020-4086-3.00033-3

Thieme, K., & Turk, D.C. (2012). Cognitive-behavioral and operant-behavioral therapy for people with fibromyalgia. *Reumatismo*. 64(4), 275-285. doi: 10.4081/reumatismo.2012.275.

Torres, X., Herrero, M. J., Mart, M., Conesa, A., Valdés, M., Arias, A., & Collado A. (2013). Why people with fibromyalgia persist in activity despite the increasing pain? A Delphi Study of the content of the Clinic Scale of Persistence in Activity in Fibromyalgia. *Revista de psiquiatría y salud mental*, 6(1), 33–44. doi: 10.1016/j.rpsm.2012.03.001.

Valls, C. (2007) Differential diagnosis of pain and fibromyalgia. *Anuario de Psicología*, 39(1), 87-92. <http://revistes.ub.edu/index.php/Anuario-psicologia/article/view/8396>

van Middendorp, H., Lumley, M.A., Moerbeek, M., Jacobs, J. W. G., Bijlsma, J.W. J., & Geenen, R.

(2010). Effects of anger and anger regulation styles on pain in daily life of women with fibromyalgia: A diary study. *European Journal of Pain*, 14(2), 176–182. doi:

10.1016/j.ejpain.2009.03.007. Vázquez, F.L. (2002). Problem solving techniques applied to major depression. *Psicothema*, 14(3), 516–522.

<http://www.psicothema.com/english/psicothema.asp?id=759>

Segura-Jiménez, V., Borges-Cosic, M., Soriano-Maldonado, A., Estévez-López, F., Álvarez-Gallardo,

I.C., Herrador-Colmenero, ... Ruiz, J.R. (2017). Association of sedentary time and physical activity with pain, fatigue and impact of fibromyalgia: the al-Ándalus study. *Scandinavian Journal of*

Medicine and Science in Sports, 27(1) 2017, 83-92

Seo, J., Kim, S.H., Kim, Y.T., Song, H.J., Lee, J.J., Kim, S.H., ... Chang Y. (2012) Working memory

impairment in fibromyalgia patients associated with altered frontoparietal memory network.

PLoS One. 7(6), e37808. doi: 10.1371/journal.pone.0037808.

Winkelmann, A, Häuser, W, Friedel, E, Moog-Egan, M, Seeger, D, Settan, M, ... Schiltenwolf M.

(2012). Physiotherapy and physical therapies for fibromyalgia syndrome. Systematic review, meta-analysis and guideline. *Schmerz*, 26(3), 276-86. doi: 10.1007/s00482-012-1171-3.

Velasco, S., Ruiz, M.T., & Álvarez-Dardet, C. (2006). Care models for non-organic somatic symptoms.

From physiopathological disorders to discomfort in women. *Revista Española de Salud Pública*, 80(4), 317-333. doi.org/10.1590/S1135-57272006000400003.

Winkelmann, A., Perrot, S., Schaefer, C., Ryan, K., Chandran, A., Sadosky A., & Zlateva, G. (2011).

Impact of fibromyalgia severity on health economic costs: Results from a European cross-sectional study. *Applied Health Economics and Health Policy*, 9(2), 125–136. doi:

10.2165/11535250-000000000-00000.

Wuytack, F., & Miller, P. (2011). The lived experience of fibromyalgia in female patients, a phenomenological study. *Chiropractic and Manual Therapies*, 19 (19), 22. doi: 10.1186/2045-709X-19-22.

Table 1. Socio-demographic and clinical data of the FM patients that participated in the GPST groups

Socio-demographic data	
	n= 44*
Gender (n females, %)	42 (97.7%)
Age, M (SD)	61.1 (8.2)
Employment status, n^o (%)	
Unemployed	3 (7.0%)
Active worker	3 (7.0%)
Paid employment but on sick leave	1 (2.3%)
Retired/pensioner	20 (46.5%)
Permanent disability	6 (14.0%)
Others	7 (16.3%)
Missing	3 (7.0%)
Clinical data (M, SD)	
Time between the onset of symptoms and diagnosis (years)	9.8 (8.3)
Time living with the diagnosis (years)	

	11.6 (7.4)
Satisfaction with the healthcare system (0-10)	
	7.1 (3.1)
Satisfaction with medication (0-10)	5.2 (2.6)
Satisfaction with non-pharmacological treatments (0-10)	7.2 (2.9)

Note: One participant presents missing data in all study variables.

	<p>Partner/Family</p> <p>Friends</p>	<p>have to work. Sure, if you break a bone everybody can see it but that's not the case with this disease." (G5)</p> <p>"The rheumatologist of a specialized service and another that we witness in a proven way perfectly understands us"(G1, G2, G3, G4, G5, G6).</p> <p>"My husband does not want to know about everything that I have. He helps me but he is old-fashioned. I don't like to complain, so I just deal with it on my own" (G1,G3,G4,G5).</p> <p>"My husband does not understand me. It's difficult to talk to him" (G1, G3, G4, G5)</p> <p>"Your friends see you looking so smart that they do not believe that you have the illness" (G1,G2,G3,G4,G5,G6)</p>	<p>"Try to find common ground with your partner".</p> <p>"Go to some couples therapy together"</p> <p>"Share complaints only with those who have the same problem so they can understand what the matter is"</p> <p>"Avoid being with others who don't understand the disease"</p>
<p>Theme 5</p> <p>Significant impacts physical, psychological and social are described</p>	<p>Ongoing Pain</p>	<p>"Overload increases my pain." (G1, G2, G3, G4, G5, G6)</p> <p>"The pain is horrible. I can't get up. Sometimes I urinate in bed because I can't move." (G3)</p> <p>"I have to change my mindset. Instead of thinking that I'm feeling bad, I think that I'm fine." (G6, G3, G2)</p> <p>"The pain is there but I'm used to it." (G4, G2, G6)</p> <p>"This week I have been in really bad pain. I have been in a lot of pain but I went out every day. I forced myself." (G6, G4, G2)</p> <p>"Meditation is the best for me. It leaves my mind go blank." (G6)</p>	<p>"Rest"</p> <p>"Look for the reasons for the pain, and try to change negative emotions"</p> <p>"Avoid thinking about the pain"</p> <p>"Perform only those activities that you can manage. Otherwise the next day will be worse."</p>

		<p>“Strong emotion increases the pain.” (G1, G2, G3, G4, G5, G6)</p> <p>“I have stopped using conventional medicine. The emotion and stress threw my whole body out of kilter and increased pain. I was taking huge amounts of medication and now I don’t take any. Why did it have to be this way?” (G6)</p>	<p>“Get used to pain”</p> <p>“Accept pain”</p> <p>“Endeavour to perform an activity.</p> <p>“Explore the emotions associated with the pain and try to address the causes”</p>
	Fatigue or overload: Physical and emotional burdens	<p>“Exhaustion is the worst. Time passes and I haven’t done anything.” (G1, G2, G3, G4, G5, G6)</p> <p>“I wake up tired.” (G1, G2, G3, G4, G5, G6)</p> <p>“I make myself more tired because I smoke and I don’t do any sport. I realize this, but I don’t do anything to change it.” (G2)</p> <p>“Sometimes it is better not to do something if you’re going to feel sick.” (G1, G2, G3, G4, G5, G6)</p> <p>“I felt like I was trying to move 50 tons.” (G1)</p> <p>“When I get overwhelmed I feel anxious and I get headaches and palpitations.” (G4)</p> <p>“I never talk about my problems. Instead I spend my time worrying about other people. I never put myself first” (G1, G2, G3, G4, G5, G6)</p>	<p>“Ask for help”</p> <p>“Do as much as possible”</p> <p>“Set limits”</p> <p>“Do nothing”</p> <p>“Rest more. Recognize one’s limitations”</p> <p>“Avoid fatigue”</p>
	Difficulty with daily activities	<p>“Sometimes for three days I cannot even do the laundry, or hang out the clothes. I can not do what I want, which is to work and take care of my grandkids. I could not even go on my honeymoon. You make a plan and you cannot stick to it. This happened to me on New Year’s Eve.” (G6)</p> <p>The day I try to make a greater effort than usual, such as cleaning all the glass in the house, the next day I can not even get up. I feel worse after a lot of effort” (G1, G2, G3, G4, G5, G6).</p>	<p>“Ask for help”</p> <p>“Distribute your tasks to avoid trying to do everything in one day”</p>
	Memory problems	<p>“I have memory problems. I put something away and then I don’t know where I left it.” (G1, G2, G3, G4, G5, G6)</p> <p>“I changed my technique for studying. I study different parts of the course in different rooms so that it’s easier to remember. I use different colors and it also helps me to organize myself better. Explaining the lesson to my sister also helps.” (G4)</p>	<p>“Stop worrying about forgetting” something. It will come to mind when you aren’t expecting it”</p> <p>“Look for ways of exercising your minds: use different activities to stimulate memory (e.g. reading, crafts etc.)”</p>
	Difficulty in mobility	<p>“My difficulty walking makes me angry, anxious and frustrated. It makes me rage.” (G1,G2,G3,G4,G5;G6)</p> <p>“Not being able to walk makes me overweight.” (G1,G3,G6)</p>	<p>“Stop feeling guilty”</p> <p>“Set small goals”</p>

	Allergies	<p>"I have been able to change how my cells regenerate." (G6)</p> <p>"The only medication I take is Ibuprofen. That's all. I have so many allergies that any other medication makes me worse." (G2)</p>	<p>"Take natural products "</p> <p>"Do not use strong cleaning products that contain many chemicals"</p>
	Depression	<p>"I do not think I am important, even to myself." (G1,G2,G3,G4,G5,G6)</p> <p>"I am suffering a lot and I do not want to make other people suffer because of this." (G1, G3, G4, G5)</p>	<p>"Pay attention to what really is important"</p> <p>"Put small goals each day"</p>
	Anxiety	<p>"I want to do everything and then I get anxious because I always like everything to be done properly." (G1, G2, G3, G4, G5, G6).</p> <p>"I'm always suffering." (G1, G2, G3, G4, G5, G6)</p>	<p>"Change your attitude and be less particular about things"</p> <p>"Ask for help when you need it"</p>
	Rage	<p>"Three of my family died in an accident. One of them was my daughter. I do not want to feel rage but I cannot help it. I can talk about the accident now; I could do that before." (G6)</p> <p>"I never express my anger; I swallow it." (G1, G4, G3)</p>	<p>"Be willing to say things you don't want to say"</p> <p>"Do not suppress emotions "</p> <p>"It is good to go doing activities, crafts, reading"</p>
	Loneliness	<p>"I feel very alone. I have to make food for everyone but I do not want to ask for help"(G4)</p> <p>I've been mistreated by my husband. I felt very alone (G1, G2, G3, G4, G5, G6)</p>	<p>"Learn to ask for support politely".</p> <p>"Caring for a pet makes you company and forces you to go out and do things you would not do. My dog has saved my life"</p>
	Lack of support from a partner	<p>"Not long ago men didn't even help you to throw out the rubbish." (G3)</p> <p>"Women have to be very careful when saying what they want because men often get angry and use this as an excuse to say 'No.'" (G4)</p> <p>"My husband does everything except the cooking. Well, sometimes bread with tomato and a salad." (G2)</p>	<p>"Avoid taking things the wrong way"</p> <p>"Be optimistic: see the glass half full, rather than half empty"</p>
	Abuse	<p>"I have a bad relationship with my husband. We never have sex, we never hold hands. "Because he doesn't treat me well, I want him to get a house in his home village and leave me in peace." (G6)</p> <p>"My son doesn't treat me well." (G4)</p> <p>"My son-in-law mistreats me every time he comes round." (G2)</p>	<p>"Communicate effectively and say what you are feeling. For example, write a letter explaining your thoughts and feelings about something that has happened. "</p> <p>"Avoid being anxious and do what you want".</p> <p>"Protect yourself. Look after yourself"</p>