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**‘Exercise to me is a scary word’: Perceptions of fatigue, sleep dysfunction and exercise in people with fibromyalgia syndrome: a focus group study**

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## **‘Exercise to me is a scary word’: Perceptions of fatigue, sleep dysfunction and exercise in people with fibromyalgia syndrome: a focus group study**

### *Abstract*

Purpose: To explore the perceptions of fatigue and sleep dysfunction, and exercise in people with fibromyalgia syndrome (FMS).

Method: Three focus groups were conducted with people with FMS.

Participants were recruited from patient support groups who had experienced therapeutic exercise in the management of their condition.

Focus groups were video and audio recorded and transcriptions analyzed for thematic content by three independent evaluators.

Results: Fatigue, sleep dysfunction and pain were universally reported by participants. The over-arching theme to emerge was a lack of understanding of the condition by others. A huge sense of loss was a major sub-theme and participants felt they had fundamentally changed since the onset of FMS. Participants reported that they were unable to carry out their normal activities, including physical activity and exercise. The invisibility of FMS was associated with the lack of understanding by others, the sense of loss and the impact of FMS.

Conclusion: People with FMS perceive that there is a lack of understanding of the condition among health care professionals and the wider society. Those with FMS expressed a profound sense of loss of their former ‘self’, part of this loss was the ability to engage in normal exercise and physical activity.

Key words: Fibromyalgia syndrome; fatigue; exercise; sleep dysfunction; physiotherapy; focus group; sleep dysfunction

## **Implications for Rehabilitation**

### **Introduction**

Fibromyalgia syndrome (FMS) is a common and complex condition, the cardinal features of which include: chronic widespread musculoskeletal pain, fatigue, sleep disturbance and physical and psychological impairment [1]. The prevalence of FMS across Europe was reported to be 4.7% [2], with women affected much more commonly than men (female: male ratio 7:1) [1]. The effect of FMS on the individual is profound, with FMS reportedly having a negative impact on the quality of life (QoL) of sufferers similar to that of rheumatoid arthritis, osteoarthritis, and systemic lupus erythematosus [3]. FMS has a substantial impact on daily life, limiting patients' functioning and negatively affecting emotional well-being [4].

The management of FMS remains problematic, no single treatment has been found to be universally effective [5]. However, recent guidelines emphasise the importance of aerobic exercise in FMS [6] and some studies have demonstrated positive outcomes with exercise interventions [7, 8]. Häuser et al. [9], for example, in a comprehensive systematic review and meta-analysis (35 RCTs; n=2494) on the use of aerobic exercise in FMS, concluded that aerobic exercise reduced pain (-0.31 [-0.46, -0.17]; p<0.001), fatigue (-0.22 [-0.38, -0.05]; p=0.009), depressed mood (-0.32 [-0.53, -0.12]; p=0.002) and limitations of health-related QoL (-0.40 [-0.60, -0.20]; p< 0.001). However, many of those with FMS are unable to tolerate aerobic exercise interventions [10], and do not believe that exercise reduces their pain [11], often leading to poor adherence to prescribed exercise programmes [12].

Although fatigue and sleep dysfunction in FMS are consistently included among

the most burdensome symptoms of the condition, and indeed are now included in the updated FMS classification criteria [13], there has been limited evaluation of these aspects of the condition [14]. Vincent et al. [14] argue that this is due to a lack of evidence-based guidelines for the management of fatigue and the lack of effective treatment strategies.

It is important to understand patients' perceptions of fatigue, sleep dysfunction and exercise in order to inform treatment development and to gain participants' buy-in to interventions [15]. A deep and credible insight of patients' knowledge and understanding of their illness and treatment can improve treatment adherence and treatment outcomes [16]. While there has been little work to date exploring, in-depth, patients' perceptions of fatigue, sleep dysfunction and exercise in this area, some limited work has been done. For example, in a postal survey of patients with FMS (n=115) McVeigh et al. [17] reported that while 60% of patients agreed that exercise improved feelings of well-being, less than 14% of patients believed exercise reduced their pain. The major barrier to exercise, reported by 80% of respondents in this survey, was fatigue. In a focus group study describing patients' perspectives on the impact of FMS, people with FMS reaffirmed that exercise made their pain worse and that fatigue was ever-present and one of the worst symptoms [4]. Given the importance of aerobic exercise for the management in FMS the aim of this focus group study was to explore the perceptions of fatigue and sleep dysfunction and exercise in people with FMS.

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## **Methods**

A homogenous, focus group design was used as a method of data collection and followed the guidelines outlined in Creswell [18]. This approach allowed the

participants to articulate their perceptions and experiences facilitating the identification of key themes [19].

The choice of facilitator was considered from a reflexive position, i.e. the researchers were consciously aware of the potential influence that the facilitator would make on the data collection process [20]. The facilitator was a female physiotherapist who had expertise in musculoskeletal problems but not FMS specifically, and who also had experience in facilitating focus group discussions, and this served to (i) reinforce the value of the participants' contributions as experts on FMS (as they were the experts, not she), and (ii) enable the facilitator to ask questions and probe responses from a position of more general knowledge (her knowledge of exercise and fatigue in people who did not have FMS). It is accepted that the sex of the interviewer makes a difference [21] and so it was hypothesized that a female facilitator would be more able to gain trust and rapport within the expected predominantly female sample.

### ***Recruitment***

Purposive sampling was used to identify participants who had been diagnosed with FMS and who had appropriate experienced of an exercise intervention. In order to be included in this study participants had to: be at least 18 years of age; they had to have met the American College of Rheumatology Criteria for FMS (1990 or 2010) [1, 13] or have a formal FMS diagnosis by a medical practitioner; participants must have had experience of therapeutic exercise interventions, organised exercise programmes, attended classes or groups of any form of exercise. Participants had to have had conversational level and basic written English language and the study was open to men and women.

Participants were recruited via a regional FMS support group. Information about the study was emailed to members of the support group and details posted on their

(members-only) Facebook page. A member of the research team also presented information about the study at one of support group meetings.

### ***Data collection***

Three focus groups were conducted in a venue that was convenient for participants and chaired by an experienced focus group facilitator. The focus groups were video and audio recorded and field notes taken. The video recording was included in order to analyse the non-verbal responses in a focus group, i.e. leaning forward, hand gestures, facing the speaker, smiles, nodding and touching, as the interactions (verbal and non-verbal) between participants is a unique feature in focus group methodology and are thus an important part of the analysis. At the start of each focus group the facilitator gave an overview of the aims of the focus group and the procedure. A semi-structured format was used, following a previously developed topic guide. The topic guide included questions about symptoms, experiences of exercise and the management of FMS. The word 'fatigue' was not used in the topic guide and questions in order to avoid leading the participants. Participants were encouraged to digress and fully explain or introduce new ideas and thoughts. When all key issues had been fully discussed and probed and no additional ones had been raised, the facilitator gave a summary of the views expressed by the group. Participants were asked to endorse these points and were given the opportunity to add any other information. The focus group ended when no further information was forthcoming. A summary of the relevant focus group was posted to each participant for verification.

The audio tapes were then transcribed verbatim by the researcher who had been present at all three focus groups. The video-recording and field notes were used to enhance the transcripts and facilitate a separate analysis of both the verbal and non-

verbal interactions between the participants. The anonymized transcriptions were stored on a password protected computer and the coded list of participants was kept in a secure data storage room. The original video and audio recordings were destroyed after transcription.

After the third focus group no new or relevant data had emerged and it was assumed that data saturation had occurred.

### ***Ethics***

Ethical approval for this study was granted by the Ulster University's Research Ethics Committee REC/13/0096. All participants gave written informed consent.

### ***Analysis***

Data were analysed by means of thematic content analysis, i.e. the themes were derived following a rigorous process of coding, categorizing, discussion and reflection [22].

Three members of the research team independently read and re-read the transcripts to allow immersion in the data. Following a data-driven inductive approach [23], general categories were identified from the transcripts and independent open coding of the data carried out. This was followed by a consensus meeting where there was discussion of key categories and themes began to emerge. Two further consensus meetings were held by the research team. Participant quotes were extracted from the data and used to illustrate the emerging themes and subthemes.

A separate analysis was then undertaken to examine the verbal and non-verbal interactions between the participants. The verbal interactions were coded and categorised in terms of whether participants changed their minds, the levels of agreement or disagreement, and the purpose of the interaction e.g. to be supportive, seek

advice etc. The non-verbal interactions related to gestures, facial expressions and other actions.

## **Results**

Fourteen people with FMS (12 female and two males) participated in the three focus groups. Four participants were in paid employment (one part-time), one was self-employed part-time, one was a volunteer worker, two were currently on sick leave due to FMS, and six were no longer working due to their FMS.

The over-arching theme that emerged from the three focus groups was the perception that there was a complete lack of understanding of the impact of FMS on sufferers. Subthemes to emerge were a profound sense of loss and the impact of symptoms on the participants. Threaded throughout these themes were three cross-themes relating to exercise, stress and the invisibility of FMS.

### ***Lack of Understanding***

A lack of understanding was the central theme to emerge from all the focus groups data. It encompassed all the sub-themes and permeated all discussions. The perceived lack of understanding by others of FMS was thought to have an effect on work, social and family life. Participants were unaware of the functional limitations of FMS, prior to their diagnosis as many had never heard of the condition and did not understand what the diagnosis really meant for them.

Within this overarching theme, participants identified distinct groups of people who did not understand them or their experience, these included healthcare providers, friends and family. There was considerable frustration at this lack of understanding, especially directed at the medical profession in regard to FMS diagnosis, treatment and

condition management: “you come out of the doctor’s [clinic] and go ‘what was the point of even going in there?’”(PT11). Participants reported that understanding and empathy for the sufferers and their personal situation was important, and would enable any treatment to be more effective:

PT8: “somebody who understands and has empathy for you and so you don’t feel judged or pushed or pressured. Someone who just gives you a bit of empathy and doesn’t just say to you, ‘could you not keep trying?’ because I would if I could. I don’t need you to tell me to keep trying....just a bit of understanding and empathy would be a great start.”

The lack of understanding increased the level of stress that the participants felt and this was also related to the cross-themes of exercise and invisibility. Participants felt that the impact that exercise and physical activity had on them was not understood and there was little empathy from society including the medical profession. This was demonstrated when others suggested “you should try and do this, you should try and do that” (PT8) with little understanding of the consequences for the person with FMS, i.e. “well, for the next three days I’m not going to be able to move from the bed”(PT8) and “then a day or two later you really suffer for it” (PT1).

The invisibility of FMS was felt to increase stress due to the need of those with FMS to keep explaining and justifying themselves and their condition.

PT13: “You look alright on the outside [rolling her eyes]. People don’t understand. For me, I take a lot of panic attacks [pause], a lot of the anxiety would be situational as well, depending on what your day to day stress levels are. My stress levels are just shocking at the minute”.

### *Sense of loss*

Participants commented on the changes experienced since the onset of their condition. This was expressed as a sense of loss of personhood, [24] the wish to “go back to the way I was” (PT13), or “I feel less of a person than I used to. It’s like I’ve lost the other [own name] and this new [own name]...and I’m not a 100% happy with her because of the because of the things I can’t do” (PT7). This description of a pre-FMS versus post-FMS self, articulated the nature of the loss experienced, and participants gave examples of their prior abilities to illustrate the extent of their loss. “I used to throw men out of bars for God’s sake, [sounding very frustrated] and lift the barrels of beer you know [shaking his head]” (PT3). Although this loss was a significant issue for participants, their perception was that others, including friends and family, did not understand this loss, and this added to the challenges they faced.

The loss expressed impacted across all aspects of participants’ lives; family life, work roles, social life and their ability to maintain housekeeping standards to the level prior to the onset of FMS. The loss of identity and the necessity of coping with this ‘new person’, was difficult, to the extent that one person stated “I’m thirty eight and just...my life...my life has been stolen [Becomes very emotional and upset]” (PT2).

Exercise was seen as another aspect of their lives that they had been forced to change due to their FMS, something that had once been important to them, that was now being discussed in the past tense “I miss it [exercise] badly and I keep trying (voice breaking and becoming emotional)” (PT8). This lack of ability to exercise was linked to feelings of loss and change, but it was also linked to fear, anxiety and stress.

Participants indicated that there was a choice to be made with regard to activities.

Prioritizing and pacing were essential and exercise would fall down the priority list

where they “weighed up” the consequences of the various family and work commitments.

PT8: “you have to make choices all the time and I think that’s the big difference between not having fibromyalgia and having fibromyalgia. If you were the normal ‘me’ you wouldn’t have to make the choice. She [referring to her ‘other’/’normal’ self] would clean the house, go to the exercise class, go out for dinner,... but the ‘me’ now? My mind has to go ‘do I Hoover and do the dishes, or do I go out for dinner?’ What do I do?” [at the end of this statement, her voice has changed from being strong and energized, to being low with little energy].

### ***Impact of symptoms***

Participants described symptoms as being either physical or psychological, and they were clear that the symptoms impacted (negatively) on both themselves as well as others. The main symptoms related to fatigue, sleeplessness, anxiety, and low mood. These symptoms impacted on the participants’ ability to exercise and were thus associated with the sense of loss and the difficulties that others had in understanding the impact of these symptoms on the person with FMS. When asked about exercise specifically, the participants across all three groups re-defined exercise and compared ‘then’ with ‘now’. This cross-theme linked to the other themes of lack of understanding and sense of loss, as participants described what they used to be able to do and how others did not understand how their capacity for exercise had changed. One participant summed up the re-defined exercise when she said even the energy “that you have to put into getting up and getting out to work, is horrendous...Even doing your normal everyday chores, even washing your hair and brushing your teeth is a lot of work” (PT14). The participants were all wary of exercise as they were sometimes able to walk,

work or socialize in the same way as they had in the past, but then they would be 'punished', and many described prolonged negative after-effects of exercise such as extreme pain or fatigue. These consequences of exercise led to avoidance of exercise "exercise to me is a scary word" (PT8), and the change in attitude regarding what activities were or were not achievable.

### *Physical symptoms*

When considering the impact of physical symptoms on 'self' "there is not an aspect of your life that this condition does not affect" (PT14), and the physical symptoms were often referred to a self-sustaining vortex emphasizing the cyclical nature of the condition, a situation from which they could not escape.

PT13: "for me the pain and fatigue are linked like this [interlocking fingers together]. They just come hand in hand and I can't say I don't get one without the other. I have them both, and if the pain is bad, the fatigue is bad, and if the fatigue is bad, then the pain is bad..... The pain makes you really fatigued.....so it's just a knock on, so you are constantly just going round and round [drawing a circle with her hand] in the same cycle you just can't get out of it".

Participants reported that they could not identify where each symptom started, only that they were all linked together which contributed to the frustration of the condition and not being able to escape the cycle of symptoms.

PT10: "I think you get frustrated with yourself, because the things that you used to be able to do, you can't do. When you go to try to do them and you can't do them then that is frustrating, then that brings you down and you get annoyed with yourself and they say that makes your fibromyalgia worse, so it's like (drawing a big circle with her finger) a vicious circle you are going in."

Sleeplessness was a concern for participants and many expressed feelings of anxiety and dread associated with going to bed, because they knew they would not sleep. Night was described by some as a “lonely” time and again the impact of not being able to sleep on day to day functioning was described as “an absolute nightmare” (PT11).

The unpredictability and invisibility of symptoms combined with the inability of others to understand the magnitude of the effect and the adaptations that participants’ had to make to their lives to cope with symptoms, added to the impact of FMS on the participants’ daily lives at home, work and socially.

PT8: “just because I can walk to the shop one day doesn’t mean I can walk to the shop the next day, and that’s hard for people who don’t have it [FMS] to understand, because they’re like ‘You’re just being lazy, sure you walked to the shop yesterday.’” The physical symptoms that resulted from exercise shaped the attitudes and feelings associated with exercise and physical activity.

### ***Psychological symptoms***

The psychological effects of FMS, such as anxiety, feelings of low mood and distress were recognized by most members of the focus groups. The participants suggested that these needed to be addressed with empathy and understanding in order to optimise the effectiveness of treatment for FMS. Most participants, however, were keen to emphasize that while they recognized that FMS had a psychological component they felt that this was not the cause of the symptoms. Many went so far as to explicitly state that FMS was “real” and emphasised the physical nature of FMS despite its “invisibility”. Many attributed a physical cause to the onset of FMS and others an emotional stressor. Participants often referred to physical or emotional events that

“triggered” FMS that had been “lying dormant”. This led to one participant observing “there is really not just the physical portion of taking away the pain. It won’t all be taken away unless you get to the root of the trauma” (PT9).

The psychological effects of FMS were also identified as potential barriers to exercise as well as contributing to the weight gain that is often associated with FMS. Participants reported that their inability to exercise and low mood (which participants linked to comfort eating), resulted in weight gain.

Stress featured prominently in all three focus groups and was associated with the invisibility and lack of understanding of FMS. Further the cyclical nature of FMS and the interaction of symptoms, made the symptoms harder to cope with. Cognitive symptoms, in particular, were made worse by stress and stressful situations. The physical and psychological symptoms of FMS and the energy required to deal with them were seen as stressors. Examples given were pain, and a lack of tolerance for light, noise and stressful situations.

PT8: “you are stressed because you are in pain. You are tired and you can’t get on with your life, or your day, or you can’t take your child to the park, or whatever it is. But then any additional stress, ...then [that] definitely is going to leave you in a flare. You can only cope with the stress you already have with the illness.”

Frustration at the condition was clearly expressed by participants and was linked to the impact of the condition on function and memory and cognition difficulties this was referred to as “fibro-fog”. Some participants expressed the view that the negative effects of physical activity led to huge frustration and mood swings, and again the sense of loss of the ‘old’ identity. Frustration at FMS was also linked to how others viewed the condition and again the over-arching theme of a lack understanding of the condition’s impact on the individual’s life and that of their families.

*Insert figure 1 approximately here*

### *Interactions between the participants*

The verbal and non-verbal interactions related primarily to agreement with others and occasionally there was a minor disagreement, for example around the specific effects of named medications. In some instances a participant questioned another in order to obtain further advice or help, or learn more about a particular resource. The dominant interaction, however, was agreement, and this not only included nodding and verbal affirmations, but also developed within each focus group to encompass a consensus position on a topic. In each of the three focus groups at least one discussion led to several participants collectively adding to the 'story' as they completed each other's sentences, repeated a key word and added another, and often a participant added emphasis to support what another person had previously said.

The non-verbal interactions mirrored the verbal as participants looked at each other, displayed active listening and interest in what was being said, and often mirrored the posture of the person speaking. Gestures were used to enhance the spoken word and to illustrate the concept being presented, for example, P10 drawing a large circle in the air whilst explaining that when "...you get annoyed with yourself and they say that makes your fibromyalgia worse, so it's like a vicious circle you are going in", as quoted above. During the discussions, some participants became emotional as they recounted an event or history, and each time, the other participants offered physical and verbal support by leaning over and touching the person (displaying empathy and solidarity), getting a drink of water, or by verbally prompting and helping the participant.

The theme that emerged from the interactions was community with the sub-themes of identity and support. Both the verbal and non-verbal interactions contributed

to the development of the focus group participants themselves being a group of people with a common identity, a community. This was illustrated by participants starting the discussions using 'I' and 'me' and ending with 'we' and 'us'. Alongside this identity was the support they gave each other throughout the focus group discussions. The interaction theme also reinforced the over-arching theme of lack of understanding. The participants are not only individuals who perceive a lack of understanding from others, (they do, however, understand each other), but they are a community that is not understood.

## **Discussion**

The aim of this study was to explore the perceptions of fatigue, sleep dysfunction and exercise in people with FMS. The themes to emerge from the focus groups were that there was a complete lack of understanding of the impact of FMS on those with the condition. Participants expressed a profound sense of loss as a consequence of FMS – including the loss of the ability to engage in physical activity and exercise. The impact of symptoms on all aspects of life also emerged as a major theme and the invisibility of FMS was felt to contribute to the lack of understanding and stress associated with the condition. With regard to perceptions and beliefs about exercise, the lack of understanding of the possible negative impact on those with FMS emerged strongly from the focus groups. Previous exercise experiences were often negative and this was strongly linked to the perception that FMS and its impact were not understood by those recommending or delivering exercise interventions. Participants associated exercise with normal activities such as carrying out activities of daily living, which were difficult and often limited. Participants reported that structured exercise was something that was ‘scary’ and produced feelings of anxiety and a sense of being pushed beyond their capability.

The findings from this study echo the results of a number of other qualitative studies in the field. Raymond and Brown [25], for example, used semi-structured interviews to explore the experiences of people with FMS and reported that participants commonly identified a failure of family and the medical profession to recognize the extent of the impact of the condition. Participants in their study also highlighted that family members and medical professionals may not regard the illness as legitimate [25]. The legitimacy of FMS was also reported to be an issue identified across a number of

qualitative studies by Sim and Madden [26]. The legitimacy of FMS was linked to the invisibility of the condition and the lack of objective findings [27], which resulted in both the illness and the individual's credibility to be questioned [sim and madden]. Sim and Madden [26] reported that the invisibility and ambiguous nature of the pain suffered in FMS was found to be problematic and patients often experienced negative or unproductive encounters with health professionals. This, less than optimal experience for patients, is supported by the current study where participants emphasised the importance of understanding and empathy as central to any health care engagement.

The impact of FMS reported in the current study mirrors work by Arnold et al. [4] who also identified the main symptoms experienced as pain, fatigue, sleep disturbance, depression, anxiety, cognitive impairment and reduced employment capacity. This was also the case in our study where participants strongly linked symptoms to a sense of loss.

The impact of FMS on identity and sense of self or loss of personhood has been previously reported. Asbring [24] for example, reported that FMS can cause a radical disruption in the women's identity such that partial identity transformation can occur. Additionally, Smith and Osborne [28] conducted semi-structured interviews with patients who were no longer able to work due to chronic pain. These authors again reported that chronic pain had a debilitating impact on patients' perception of self and their identity, and, as in the current study, Smith and Osborne [28] reported that participants referred to a different 'self' before and after the onset of chronic pain. The experience of chronic pain was reported to assault and undermine participants' sense of self to the extent that participants considered that the 'self with pain' was not 'the real me' [28]. This loss of self strongly emerged from our study.

It is perhaps not surprising that the main barriers to exercise or physical activity identified in this study were fatigue, pain and a fear of exacerbating symptoms, these factors have been previously reported [29] in addition to disability, mood disturbance, low exercise self-efficacy and low social support. It has previously been reported that improving exercise self-efficacy is associated with better outcomes in FMS [30], and it is recognised that behaviour change is an important factor in the successful treatment of those with FMS, particularly when combined with exercise interventions [31,32]. Cognitive behavioural therapy interventions have been used with some limited success in FMS to improve pain, mood and disability [33], however, Michie et al. [34] has suggested that many behavioural change interventions are designed without systematically identifying the target behaviour that needs to change and matching this target behaviour to an appropriate intervention within an appropriate theoretical context. It is proposed that future research should adopt this approach in FMS.

This study had some limitations, recruitment was from a one support group and the nature of the study means that there is limited generalizability. However, the themes and subthemes that emerged from this study are consistent with the previous literature.

## **Conclusion**

This study has identified that those with FMS perceive a lack of understanding of their condition and experience a profound sense of loss as a result of their FMS. This sense of loss extends to their inability to engage with physical activity and exercise. Engaging in exercise intervention is a major challenge for those with FMS, health care professionals should appreciate the enormity of this challenge and approach exercise prescription with empathy and understanding.

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## References

- [1] Wolfe F, Smyth HA, Yunus MB et al. The American College of Rheumatology Criteria for the classification of Fibromyalgia. Report of the multicentre criteria committee. *Arthritis Rheum.* 1990;33(2):160-72.
- [2] Branco JC, Failde I, Blotman F et al. Prevalence of fibromyalgia: a survey in five European countries. *Semin Arthritis Rheum.* 2010;39(6):448-53.
- [3] Zautra AJ, Fasman R, Parish BP et al. Daily fatigue in women with osteoarthritis, rheumatoid arthritis, and fibromyalgia. *Pain* 2007;128(1-2):128-135.
- [4] Arnold LM, Crofford LJ, Mease PJ et al. Patient perspectives on the impact of fibromyalgia. *Patient Educ Couns.* 2008;73(1):114-20.
- [5] Okifuji A, Donaldson GW, Barck L et al. Relationship between fibromyalgia and obesity in pain, function, mood, and sleep. *J Pain.* 2010;11(12):1329-37.
- [6] Macfarlane GJ, Kronisch C, Dean LE et al. EULAR revised recommendations for the management of fibromyalgia. *Ann Rheum Dis.* 2016 Jul 4. pii: annrheumdis-2016-209724. doi: 10.1136/annrheumdis-2016-209724. [Epub ahead of print].
- [7] Sañudo B, de Hoyo M, Carrasco L et al. Effect of whole-body vibration exercise on balance in women with fibromyalgia syndrome: a randomized controlled trial. *J Altern Comp Med.* 2012;18(2):158-64.
- [8] Sañudo B, Carrasco L, de Hoyo M et al. Effects of exercise training and detraining in patients with fibromyalgia syndrome: a 3-yr longitudinal study. *Am J Phys Med Rehabil.* 2012 Jul;91(7):561-9.
- [9] Hauser W, Klose P, Langhorst J et al. Efficacy of different types of aerobic exercise in fibromyalgia syndrome: a systematic review and meta-analysis of randomized controlled trials. *Arthritis Res Ther.* 2010;12(3):R79.

- [10] Mengshoel AM, Vøllestad NK, Førre O. Pain and fatigue induced by exercise in fibromyalgia patients and sedentary healthy subjects. *Clin Exp Rheumatol*. 1995;13(4):477-82.
- [11] McVeigh JG, Millar A, Hurley DA et al. Patients' perceptions of exercise therapy in the treatment of fibromyalgia syndrome. *Musculoskeletal Care* 2003;1:98-107.
- [12] van Santen M, Bolwijn P, Landewe R et al. High or low intensity aerobic fitness training in fibromyalgia: does it matter? *J Rheumatol*. 2002;29(3):582-7.
- [13] Wolfe F, Clauw DJ, Fitzcharles MA et al. The American College of Rheumatology preliminary diagnostic criteria for fibromyalgia and measurement of symptom severity. *Arthritis Care Res (Hoboken)*. 2010;62(5):600-10.
- [14] Vincent A, Benzo RP, Whipple MO et al. Beyond pain in fibromyalgia: insights into the symptom of fatigue. *Arthritis Res Ther*. 2013;15(6):221.
- [15] Sluijs EM, Kok GJ, van der Zee J. Correlates of exercise compliance in physical therapy. *Phys Ther*. 1993;73(11):771-82.
- [16] Martin LR, Williams SL, Haskard KB et al. The challenge of patient adherence. *Ther Clin Risk Manag*. 2005;1(3):189-99.
- [17] McVeigh JG, Lucas A, Hurley DA et al. Patients' perceptions of exercise therapy in the treatment of fibromyalgia syndrome: a survey. *Musculoskeletal Care*. 2003;1(2):98-107.
- [18] Creswell John W. *Qualitative Inquiry and Research Design. Choosing among Five Approaches* 3rd Ed. California: Sage Publications; 2013.
- [19] Ravitch SM, Riggan M. *Reason and Rigor: How conceptual frameworks guide research*. California: Sage Publications; 2012.

- [20] Wanda P. Confession, catharsis or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *Int J Qual Stud Educ.* 2003;16(2):175-196.
- [21] Denzin NK, Lincoln YS. Eds. *Handbook of Qualitative Research* 2nd Ed. California: Sage Publications; 2000.
- [22] Bazeley P. *Qualitative Data Analysis: Practical Strategies.* Research Support Pty Limited; Australia 2013.
- [23] Boyatzis RE. *Transforming qualitative information: Thematic analysis and code development.* London: SAGE;1998.
- [24] Asbring P. Chronic illness -- a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *J Adv Nurs.* 2001;34(3):312-9.
- [25] Raymond MC, Brown JB. Experience of fibromyalgia. Qualitative study. *Can Fam Physician.* 2000;46:1100-6.
- [26] Sim J, Madden S. Illness experience in fibromyalgia syndrome: a meta-synthesis of qualitative studies. *Soc Sci Med.* 2008;67(1):57-67.
- [27] Madden S, Sim J. Creating meaning in fibromyalgia syndrome. *Soc Sci Med.* 2006;63(11):2962-73.
- [28] Smith J A, Osborn M. Pain as an assault on the identity: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health.* 2007;(22):517–534.
- [29] Arnold LM. Biology and therapy of fibromyalgia. *New therapies in fibromyalgia. Arthritis Res Ther.* 2006;8(4):212.
- [30] Busch AJ, Webber SC, Brachaniec M, et al. Exercise therapy for fibromyalgia. *Curr Pain Headache Rep.* 2011;15(5):358-367.

[31] van Koulil S, van Lankveld W, Kraaijmaat FW et al. Tailored cognitive-behavioural therapy and exercise training improves the physical fitness of patients with fibromyalgia. *Ann Rheum Dis.* 2011;70(12):2131-3.

[32] Fitzcharles MA, Ste-Marie PA, Goldenberg DL et al. National Fibromyalgia Guideline Advisory Panel. 2012 Canadian Guidelines for the diagnosis and management of fibromyalgia syndrome: executive summary. *Pain Res Manag.* 2013;18(3):119-26.

[33] Bernardy K, Klose P, Busch AJ et al. Cognitive behavioural therapies for fibromyalgia. *Cochrane Database Syst Rev.* 2013 Sep 10;(9):CD009796.

[34] Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci.* 2011;6:42.