

The impact of chronic pain on the sexuality of women with fibromyalgia: a clinical-qualitative study¹

Neftali Beatriz Centurion & Rodrigo Sanches Peres
Instituto de Psicologia, Universidade Federal de Uberlândia, Brazil

Fibromyalgia is a rheumatologic syndrome characterized by the presence of chronic, non-inflammatory and widespread musculoskeletal pain, predominantly affecting

middle-aged women. It is generally accompanied by memory, attention, mood and sleep disorders, as well as fatigue and headaches. According to the criteria proposed by the American College of Rheumatology (ACR) in 2010, its diagnosis is based on the presence of the following conditions for more than three months: (1) pain in at least seven out of 19 pre-established anatomic sites, while the patient has to score at least five points on a scale of associated symptoms – among which are depression and anxiety – or (2) pain between three and six sites and at least nine or more points on the scale of associated symptoms (Wolfe et al., 2010).

Considering that chronic pain is the primary symptom of fibromyalgia, there is an expectation that it will affect the sexual lives of patients. We performed a literature review (Centurion & Peres, 2016) including empirical studies on the topic, and found that most of the studies report that fibromyalgia is associated with many sexual problems in women, including reduced sexual desire and satisfaction. The utilization of quantitative methodology and self-report instruments addressing sexual dysfunction were predominant in these studies, as exemplified by

Blazquez et al. (2015), and Burri, Lachance and Williams (2014). Sexuality, however, has subjective aspects that are not easily be apprehended by the quantification of certain occurrences – related, for example, to the presence of symptoms of sexual dysfunction.

Therefore, qualitative research that focuses on sexuality from a broader perspective – this is, a perspective not limited to sexual dysfunction – can contribute to the advancement of current knowledge on this topic, as such data collection strategies allow participants to express themselves more freely and attempt to both describe and interpret the meanings held by fibromyalgia patients regarding sexuality. To our knowledge, there is only one previous qualitative study in this area, which was conducted by García-Campayo and Alda (2004) who found that decreased sexual desire was related to a fear of experiencing musculoskeletal pain after sexual intercourse. Thus, we conducted a qualitative study aiming to understand how women with fibromyalgia experience sexuality. This paper is part of this study and more specifically addresses the impact of chronic pain on sexuality from the participants' perspective.

Better understanding concerning the impact of chronic pain on patients' sexuality is still needed to support multidisciplinary interventions intended to address this problem more directly, a problem that is usually neglected or relegated to a secondary plan in therapeutic regimes (Bazzichi et al., 2012). Additionally, it is interesting to note that, according to updated guidelines for fibromyalgia management from the European

¹ Support: Coordination for the Improvement of Higher Education Personnel (CAPES).

League Against Rheumatism (EULAR), treatments should be tailored to the specific needs of individuals and involve psychological therapies (Macfarlane et al., 2016). These recommendations highlight the relevance of this paper's topic to a European audience.

Method

Research design

This study followed the assumptions of the clinical-qualitative methodology. Originally proposed in Brazil by Turato (2003), the clinical-qualitative methodology is defined as a refinement of qualitative methodology arising from the human sciences but directed to life experiences in health contexts. Also, according to Turato, the clinical-qualitative methodology favors the interpretation of meanings related to the health-disease continuum from the perspectives of patients, family members, or health professionals. Hence, as in any type of qualitative study, the researcher seeks to deepen understanding regarding the object of study in a specific social group, regardless of the numerical representation of participants.

Participants

Eight women who met the following criteria were included in the study: (1) having a diagnosis of fibromyalgia for at least six months; (2) being 40 to 60 years old, since the prevalence of fibromyalgia is higher in this age group; and (3) being literate, as participants were requested to write and then read to the group a story about a woman with fibromyalgia, in order to encourage them to express how fibromyalgia impacts their daily lives. There were no restrictions regarding social class, occupation, marital status, sexual orientation or any other aspects. Most were

married, homemakers, and were 50 years old on average. Their level of education (from primary school to high school) varied and time since diagnosis ranged from 2 to 21 years. It is important to note that the participants composed a convenience sample and were recruited from a Brazilian non-governmental organization, Associação de Reumáticos de Uberlândia e Região (ARUR).

Data collection

The setting in which data collection took place was a psychoanalytic discussion group. This type of group presents the following basic characteristics: (1) meetings begin with some activity proposed by the coordinator – for example, a debate on the possible meanings of song lyrics that refer to the theme selected by the coordinator for that particular meeting – to induce associations, and at the same time, to limit the issue to be addressed; (2) has a time limitation; and (3) ideas are shared without any kind of judgment among the participants (Emílio, 2010). A total of four meetings that lasted approximately one hour and 30 minutes each were held on days and times scheduled according to the participants' availability. The meetings took place at the ARUR's headquarters and were audio recorded with the participants' consent.

Data analysis

The audio recordings were transcribed verbatim and analyzed afterwards according to the content analysis procedures recommended by Bardin (1979). Therefore, data analysis proceeded as follows: (1) free-floating reading – that is, an attitude in which none of the discursive elements are privileged a priori – was used to read data and establish initial hypotheses (pre-analysis); (2) data were grouped into preliminary categories (exploration of data); and (3) categories were

established, latent and manifested content were differentiated and inferences were elaborated (treatment of results). The categories correspond to the grouping of the participants' reports, organized by the researchers using frequentist inference, based on numerical repetitions, or by categorical analysis, based on the identification of equivalences or similarities. In this study, we adopted the second. Note that from an epistemological point of view, content analysis is compatible with the clinical-qualitative methodology because it values the analysis of data from the participants' perspectives.

Results and Discussion

Various categories emerged from the content analysis. Considering this study's objective, only one category was addressed here, the one including reports that, directly or indirectly, refer to the impact of chronic pain on sexuality from the participants' points of view. We verified in these reports that this impact was considered invariably negative. For most participants, their pain significantly decreased sexual desire or even eliminated it entirely, as Excerpts 1 and 2, respectively, show. As a consequence, the participants reported they usually refuse to have sexual intercourse with their partners, as portrayed in Excerpt 3.

Excerpt 1: "It changed everything [sexual desire after fibromyalgia] because [...] some days there's no stimulus, only pain; it sucks" (Participant S.)

Excerpt 2: "I totally lost it [sexual desire]" (Participant R.)

Excerpt 3: "Then you say [to the partner when he is interested in sex] 'would you go to sleep, for God's sake'" (Participant N.)

In general, the studies by Blazquez et al. (2015) and García-Campayo and Alda (2004) report similar results as they identify many women with fibromyalgia as presenting low frequency of sexual activity and high levels of sexual avoidance and also complain of marked decrease in sexual desire after syndrome onset due to chronic pain. This study's participants, however, indicated that despite the chronic pain, they would be more willing to have sex if their partners were more affectionate and attentive throughout the day, not just when they were interested in sex, as Excerpts 4 and 5 show.

Excerpt 4: "[...] but I guess that, if it was done with love, you'd even have intimacy everyday, it's [...] good, but you don't get a little kiss during the day, you are not hugged [by the husband], but then at night, he wants to "screw"! Everything is going to hurt!" (Participant A.)

Excerpt 5: "[...] During the day, there's no sign of affection, no attention, on the contrary, he fights with you, is mean to you for some reason. Then, at night he [husband] thinks you're ok (Participant N.)

This result is consistent with one of the conclusions reached by Burri et al. (2014), according to which dissatisfaction with the affective relationship stands out as the main predictor of sexual problems among women with chronic and widespread pain. The authors, however, do not clarify the reason for such dissatisfaction. Perhaps, this lack of clarification may be explained by the fact that only one question addressed this issue during data collection ("How satisfied are you with your current relationship?"). It is precisely in regard to current knowledge concerning this aspect that we believe this study can contribute. This is so because the aforementioned result suggests that the perceptions of women with fibromyalgia

regarding their partners' behaviors is that their manifestations of companionship and affection, not related to sexual interest, may minimize the negative impact of chronic pain on sexuality.

Conclusions

Through the innovative utilization of a psychoanalytic discussion group as the setting of the data collection in a clinical-qualitative study on sexuality among fibromyalgia patients, the obtained results reveal that, from the participants' perspectives, the negative impact of chronic pain on sexuality may be minimized by factors that ultimately are related to the engagement of their partners in the affective relationship, such as spontaneous expressions of affection on diverse occasions. It is interesting to take this result into account when addressing women with fibromyalgia within the healthcare system, especially considering the EULAR updated guidelines for fibromyalgia management. Since the results reported here were collected from a very specific convenience sample, we are limited to naturalistic generalizations rather than statistical generalizations. We emphasize, however, that the use of more open data collection strategies stands out as potentially useful for new studies addressing this topic.

References

- Bardin, L. (1979). *Análise de conteúdo* [Content analysis]. Lisbon, Portugal: Edições 70.
- Bazzichi, L., Giacomelli, C., Rossi, A., Sernissi, F., Scarpellini, P., Consensi, A., & Bombardieri, S. (2012). Fibromyalgia and sexual problems. *Reumatismo*, 64(4) 261-267. doi: 10.4081/reumatismo.2012.261
- Blazquez, A. R., Ruiz, E., Aliste, L., García-Quintana, A., & Alegre, J. (2015). The effect of fatigue and fibromyalgia on sexual dysfunction in women with chronic fatigue syndrome. *Journal of Sexual & Marital Therapy*, 41(1), 1-10. doi: 10.1080/0092623X.2013.864370
- Burri, A., Lachance, G., & Williams, F. M. (2014). Prevalence and risk factors of sexual problems and sexual distress in a sample of women suffering from chronic widespread pain. *Journal of Sexual Medicine*, 11(11), 2772-2784. doi: 10.1111/jsm.12651
- Centurion, N. B., & Peres, R. S. (2016). A sexualidade em pacientes com fibromialgia: Panorama da produção científica [Sexuality in patients with fibromyalgia: Overview of scientific production]. *Revista da SPAGESP*, 17(2), 108-119.
- Macfarlane, G. J.; Kronisch, C., Dean, L. E., Atzeni, F., Häuser, W., Fluß, E. ... Choy, E. (2016). EULAR revised recommendations for the management of fibromyalgia. *Annals of Rheumatic Disease*. Advance online publication. doi:10.1136/annrheumdis-2016-209724
- Emílio, S. A. (2010). O grupo psicanalítico de discussão como dispositivo de aprendizagem e compartilhamento [The psychoanalytic discussion group as a device for learning and sharing]. *Vínculo*, 2(7), 35-43.
- García-Campayo, J., & Alda, M. (2004). La vivencia de la sexualidad en pacientes con fibromialgia: Un estudio cualitativo [Sexuality in patients with fibromyalgia: A qualitative study]. *Archivos de Psiquiatría*, 67(3), 157-167.
- Turato, E. R. (2003). *Tratado de metodologia da pesquisa clínico-qualitativa: Construção teórico-epistemológica, discussão comparada e aplicações nas áreas de saúde e humanas* [Treaty of clinical qualitative research methodology: Theoretical-epistemological comparative discussion and application in the areas of health and human sciences]. Petrópolis, Brazil: Vozes.
- Wolfe, F., Clauw, D. J., Fitzcharles, M.-A., Goldenberg, D. L., Katz, R. S., Mease, P., ... Yunus, M. B. (2010). The American College of Rheumatology preliminary diagnostic criteria for fibromyalgia and measurement of symptom

severity. *Arthritis Care & Research*, 62(5) 600-610. doi: 10.1002/acr.20140



Neftali Beatriz Centurion
Instituto de Psicologia,
Universidade Federal de Uberlândia,
Brazil
neftalcenturion@gmail.com



Rodrigo Sanches Peres
Instituto de Psicologia,
Universidade Federal de Uberlândia,
Brazil
rodrigossanchesperes@ufu.br