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Evaluation and association of self-care agency with symptoms and quality of life in patients with fibromyalgia

Avaliação do agenciamento de autocuidados e sua associação com sintomas e qualidade de vida em indivíduos com fibromialgia

Evaluación del agenciamiento del autocuidado y su asociación con síntomas y calidad de vida de individuos con fibromialgia

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ABSTRACT | Fibromyalgia (FM) is a condition of high prevalence, which causes physical discomfort, mental distress and impairment of social relationships. Self-care may be a relevant factor to improve the quality of life in individuals with fibromyalgia, since it is related to the act of empowerment, leading individuals to have control over their own life. The aim of this study was to assess self-care agency of individuals with fibromyalgia and check for associations between self-care and symptoms, quality of life and sociodemographic variables. The study included 40 individuals with FM according to the 2010 American College of Rheumatology criteria. Self-care was measured with the Appraisal Self-Care Agency Scale-Revised (ASAS-R), pain with the Visual Analog Scale (VAS) and the Widespread Pain Index (WPI), severity of symptoms with the Symptom Severity (SS) Scale, and quality of life with the Fibromyalgia Impact Questionnaire – Revised (FIQ-R). In data analysis, the Pearson correlation coefficient was used for parametric data, and the Spearman correlation coefficient was used for non-parametric data. The level of significance adopted was 5%. Moderate values were found for self-care agency (52.75±10.25), VAS pain (5.84±2.16), WPI (13.32±3.78) and SS (9.30±1.68). Severe impact on quality of life was found with the FIQR (63.98±17.26). Additionally, significant correlations were observed of self-care agency with social status (r=0.391), and with the following FIQ-R domains: function (r=−0.338), overall impact (r=-0.315), symptoms (r=−0.332) and total score (r=−0.375). The study suggests that individuals with fibromyalgia have a moderate level of self-care agency, and a weak association of self-care with quality of life and social status.

Keywords | Fibromyalgia; Self Care; Pain; Quality of Life.

RESUMO | A fibromialgia (FM) é uma condição de alta prevalência e que causa desconforto físico, sofrimento mental e comprometimento nas relações sociais. Assim, o autocuidado pode ser um aspecto determinante para melhorar a qualidade de vida de indivíduos com FM, pois está relacionado ao ato de se investir de poder. Portanto, o objetivo deste estudo foi avaliar o agenciamento do autocuidado de indivíduos com FM e verificar a associação do autocuidado com variáveis sociodemográficas, sintomas e qualidade de vida. Participaram do estudo 40 indivíduos com FM, que preencheram os critérios diagnósticos do Colégio Americano de Reumatologia de 2010. O autocuidado foi avaliado pela Escala de Avaliação de Agenciamento de Autocuidados Revisada (EAAA-R), a intensidade da dor dos pacientes foi verificada pela Escala Visual Analógica (EVA) e pelo Índice de Dor Generalizada (IDG),

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enquanto a severidade dos sintomas foi avaliado pela Escala de Severidade dos Sintomas (SS) e a qualidade de vida pelo Questionário de Impacto da Fibromialgia Revisado (QIF-R). Utilizamos o coeficiente de correlação de Pearson (dados paramétricos) e coeficiente de correlação de Spearman (dados não paramétricos), com nível de significância $\alpha<0{,}05$. Os resultados mostram valores médios para o agenciamento do autocuidado (52,75±10,25), intensidade da dor (5,84±2,16), IDG (13,32±3,78), SS (9,30±1,68), e QIF-R (63,98±17,26). Houve associação do autocuidado com a classe social (r=0,391) e associação com domínios do QIF-R: função (r=−0,338), impacto geral (r=−0,315), sintomas (r=−0,332) e escore total (r=-0,375). O estudo sugere moderado agenciamento de autocuidado e fraca associação do autocuidado com a qualidade de vida e com a classe social em indivíduos com fibromialgia.

Descritores | Fibromialgia; Autocuidado; Dor; Qualidade de Vida.

RESUMEN | La fibromialgia (FM) es una enfermedad de alta prevalencia que causa malestar físico, sufrimiento mental y afecta las relaciones sociales. El autocuidado puede ser un aspecto determinante para mejorar la calidad de vida de individuos con FM, pues está relacionado al acto de invertirse de poder. El objetivo de este estudio fue evaluar el agenciamiento del autocuidado de individuos con FM y verificar una asociación del autocuidado con las variables sociodemográficas, síntomas y calidad de vida. En el estudio, participaron 40 personas con FM, que cumplieron con los criterios de diagnóstico del Colegio Americano de Reumatología de 2010. El autocuidado fue puntuado por la Escala de Evaluación de Agencia de Autocuidados Revisados (EAAA-R), la intensidad de dolor fue evaluada por la Escala Visual Analógica (EVA) y por el Índice de dolor generalizado (IDG), mientras que la severidad de los síntomas fue evaluada por la Escala de Severidad de los Síntomas (SS), y la calidad de vida por el Cuestionario de Impacto de la Fibromialgia Revisado (FIQ-R). Se utilizó el Coeficiente de Correlación de Pearson (datos paramétricos) y el Coeficiente de Correlación de Spearman (datos no paramétricos), con un nivel de significancia $\alpha<0{,}05$. Los resultados mostraron valores medios para el agenciamiento del autocuidado (52,75±10,25), la intensidad del dolor (5,84±2,16), el IDG (13,32±3,78), la SS (9,30±1,68) y el FIQ-R (63,98±17,26). Hubo una asociación del autocuidado con la clase social (r=0,391) y las asociaciones con los dominios del SIF-R: función (r=−0,338), impacto general (r=−0,315), síntomas (r=0,332) y puntuación total (r=−0,375). El estudio apunta moderado agenciamiento de autocuidado y baja asociación del autocuidado con la calidad de vida y la clase social en el individuo con fibromialgia.

Palabras clave | Fibromialgia; Autocuidado; Dolor; Calidad de Vida.

INTRODUCTION

Fibromyalgia (FM) is a chronic rheumatic condition that affects an individual's functional capacity and quality of life, with an impact on daily activities. It is characterized by widespread muscular pains, lasting more than three months, and symptoms such as sleep problems, irritability, fatigue, headache, anxiety and troubles with memory[1]. The prevalence of this disease in the Brazilian population is 2%, with a higher rate among female individuals (from 2.4% to 6.8%) aged between 35 and 60 years[2].

Due to the chronicity of FM, self-care appears as a method to support conventional treatments of this syndrome, as it promotes patient empowerment. According to the Ministry of Health, self-care basically places patient as the center of any change in his own life and health, the one who most knows his inherent situation, knowing what he needs to feel good and what favors or hinders change processes[3]. The exercise of patient empowerment is based on offering materials that promote basic techniques of looking at oneself, observing and choosing actions and ways to take care of one's own health, control symptoms, perform daily activities and suggest ways to incorporate well-being activities in one's daily life[2,3], as well as adherence to all elements of the therapeutic plan. Self-care agency can be defined as the ability of an individual to continuously assess his or her health-related needs and perform self-care activities related to well-being, health promotion and maintenance[4].

One of the instruments used to assess self-care is the Appraisal Self-Care Agency Scale (ASAS), developed by a group of American and Dutch investigators belonging to the Conference Group in Nursing Development. ASAS has 24 items and five answer options of Likert scale type to assess health-promoting behaviors[4]. This study used a version of ASAS-Revised, adapted to the Brazilian context and validated by Damásio[4].

In clinical practice, an individual's active role in self-care is very important for a successful treatment. However, studies and instruments that assess self-care in FM are rare, and few are known and used by health professionals.

Considering the above, this study aimed to assess self-care agency of individuals with FM and check for associations of self-care with sociodemographic variables (sex, age, marital status, education, time since onset of disease, social status and FIQ-R), in addition to symptoms (VAS, WPI and SS) and quality of life.

METHOD

This is a cross-sectional observational study, published by the Jornal da Universidade de São Paulo (USP) and associated social media. A total of 117 volunteers attended the Teaching and Research Center of the Department of Physical Therapy, Speech Therapy and Occupational Therapy at the Faculdade de Medicina da Universidade de São Paulo, and the Clinical Physical Therapy Investigation and Electromyography Laboratory, for evaluation and screening, which consisted of answering an assessment questionnaire. Of these volunteers, 43 individuals met the inclusion criteria of the study.

Inclusion criteria were: participants had to be 19 to 59 years old, meet the diagnostic criteria of 2010 American College of Rheumatology[5], and have completed basic education. The following exclusion criteria were considered, considering each participant's self-report: have other conditions causing chronic pain (neuropathy, rheumatoid arthritis, osteoarthritis, spinal stenosis or cancer), have a severe mental disorder (schizophrenia, psychosis, bipolar affective disorder or severe depression), and have a visual impaired or a hearing impairment.

The sample calculation was based on health-related quality of life (HRQoL), a continuous quantitative variable measured using the Fibromyalgia Impact Questionnaire – Revised (FIQ-R), with a standard deviation of 24.3[6] and considering 14% with relevant minimum difference[7]. Using 80% power and a significance level of 5%, a minimum number of 30 participants was obtained, with the sample size of 40 individuals.

This study is linked with the doctoral project "Development of a mobile application to promote self-care in patients with fibromyalgia," approved by the Research Ethics Committee of the Faculdade de Medicina da Universidade de São Paulo, nº 274/14. All participants signed an informed consent form.

PROCEDURE

Sociodemographic data of participants, such as age, sex, marital status, education, time since onset of disease and social status, were collected with a questionnaire applied by the rater, based on the number of minimum wages (one minimum wage = R$937) as average family income, classified into the following categories: A (>R$18,740), B (R$9,370-R$18,740), C (R$3,748-R$9,370), D (R$1,874-R$3,748) and (<R$1,874).

ASSESSMENT OF SYMPTOMS

Pain

The Visual Analog Scale (VAS) assessed the pain the individual felt at that moment. It is an instrument that consists in a 10 cm long straight line, with its ends defining extreme limits: 'no pain at all' and 'pain as bad as it could be.' The closer to 10 centimeters, the greater the intensity of pain[8]. Mild pain is classified as ≤3.4 centimeters, moderate pain is 3.5 to 7.4, and severe pain ≥7.5 cm[9]. In addition, the Widespread Pain Index (WPI) was used, which consists of a list of 19 body regions and the patient must check all regions where he felt pain in the last week. The result of the WPI corresponds to the total number of places with pain, that is, the closer to 19, the higher the WPI[5].

Severity of symptoms

Severity of symptoms was measured using the Symptom Severity (SS) Scale, with four items: fatigue, non-restorative sleep, cognitive symptoms and somatic symptoms. Each item uses a four-point Likert scale, whose score ranges from 0 to 3. The SS score corresponds to the sum of the results obtained in each item, which can vary from 0 to 12. The closer to 12 points, the greater the severity of these symptoms[5]. The WPI and SS are part of the new criteria for fibromyalgia diagnosis developed by the American College of Rheumatology in 2010.

Quality of life

Quality of life was measured using the Fibromyalgia Impact Questionnaire – Revised (FIQ-R), validated for

Brazilian Portuguese[6], which consists of the following domains: function, general impact and symptoms. The total score corresponds to the sum of the scores of all three domains, ranging from 0 to 100. The higher the total score, the greater the impact of FM on quality of life[6,10]. The total score in FIQ-R is classified as mild from 0 to 39, moderate between 39 and 59, and severe ≥59 to 100[7].

Self-care

Self-care was measured using the Appraisal Self-Care Agency Scale-Revised (ASAS-R), validated for Brazilian Portuguese[11]; it consists of 15 statements assessed using a five-point Likert scale, ranging from 1 to 5. Sin items 4, 11, 14 and 15 have negative content, the scores have to be inverted. The total score corresponds to the sum of the results obtained in each item, ranging from 15 to 75 points. Higher values indicate a greater capacity for self-care[4,12]. The scale also classifies self-care based on a structure consisting of three factors: (1) having power to self-care; (2) developing power to self-care; and (3) lacking power to self-care[4].

DATA ANALYSIS

A descriptive statistical analysis was conducted to check for associations between sociodemographic and clinical variables (pain, symptom severity and quality of life) and the patient's self-care variable using the Pearson correlation coefficient for parametric data and the Spearman correlation coefficient for non-parametric data. The correlation coefficient was assessed qualitatively according to the following criterion: excellent correlation r>0.75, moderate correlation 0.40≤r<0.75, weak correlation r<0.40[13]. A significance level of 5% was adopted. All analyses were performed using Sigma Plot (Syst at Software, Inc.).

RESULTS

Table 1 shows the demographic and clinical data of participants. Most were female (97.5%), aged between 24 and 59 years, 42.5% were married, 42.5% from social classes D and E, and 62.5% with years of education >12. Time since onset of disease ranged from a minimum of one month from diagnosis to a maximum of 20 years. The WPI (13.32) showed high values in relation to the areas affected by pain, and the pain intensity was moderate (5.84). The impact of fibromyalgia showed severe values in quality of life (63.98), high values in the severity of symptoms (9.3) and moderate self-care agency (52.75).

Table 1. Sociodemographic and clinical data of the sample (n=40)

Sex	
Female (%)	39 (97.5%)
Age (mean±SD)	42.7±10.12
Marital status (%)	
Single	13 (35.5)
Married	17 (42.5)
Divorced (a)	8 (20)
Widow/widower	2 (5)
Social class (%)*	
D+E	17 (42.5)
C	15 (37.5)
A+B	8 (20)
Years of education	
0-8	2 (5)
9-12	13 (32.5)
>12	25 (62.5)
Time since onset of disease in years (mean±SD)	8.01±5.4
WPI (0-19)	13.32±3.78
VAS pain (0-10)	5.84±2.16
FIQ-R 0-100 (mean±SD)	63.98±17.26
Function (0-30)	17.19±6.98
Impact (0-20)	12.4±5
Symptoms (0-50)	33.24±7.85
SS (0-12)	9.3±1.68
Self-care (15-75)	52.75±10.25
Factor 1 (6-30)	22.45±6.77
Factor 2 (5-25)	20.95±10.5
Factor 3 (4-20)	14.57±27.44

WPI: Widespread pain index; SS: Symptom severity; FIQ-R: Fibromyalgia Impact Questionnaire – Revised; VAS: Visual Analog Scale; Factor 1: having power to self-care; Factor 2: developing power to self-care; Factor 3: lacking power to self-care; *minimum wage in 2017, according to the Brazilian Institute of Geography and Statistics (IBGE).

Table 2 shows the results of each item of the Appraisal Self-Care Agency Scale-Revised (ASAS-R). The statements that obtained the best scores favoring self-care were 7 and 12 about the search for information in case of prescription of a new medication or when feeling that health was threatened, while the statements with the worst self-care scores were 4 and 15, indicating that, in general, the participants feel they lack energy and capacity for self-care. Since it does not require the total sum of the score, it was not necessary to invert the score of items 4, 11, 14 and 15 to calculate these results.

Table 2. Classification of ASAS-R items based on its factor structure

Factors of the scale	Mean by factor	Mean (SD)	Median
Factor 1: Having power to self-care	22.46		
01. As circumstances change, I make the necessary adjustments to stay healthy.		3.63 (1.29)	4
02. If my physical mobility is reduced, I make the necessary adjustments.		3.78 (1.27)	4
03. When necessary, I establish new priorities in my attitudes to stay healthy.		3.8 (1.09)	4
05. I look for better ways to take care of myself.		3.75 (1.19)	4
06. When necessary, I find time to take care of myself.		3.5 (1.15)	4
10. I often assess the effectiveness of the things I do to stay healthy.		4 (1.01)	4
Factor 2: Developing power to self-care	20.96		
07. If I take a new medication, I look for information about its side effects to take better care of myself.		4.45 (1.18)	5
08. I changed some of my old habits to improve my health.		3.95 (1.34)	4.5
09. I often take measures to ensure my safety and the safety of my family.		4.28 (0.88)	4
12. I am able to get the information I need when my health is threatened.		4.4 (0.87)	5
13. I seek help when I feel unable to take care of myself.		3.88 (1.28)	4
Factor 3: Lacking power to self-care	14.65		
04. In general, I don't have the energy to take care of myself as I should.		4.15 (1.05)	5
11. In my daily activities, I rarely dedicate time to take care of myself.		3.15 (1.42)	3.5
14. I rarely have time for myself.		3 (1.36)	3
15. I am not always able to take care of myself the way I want to.		4.35 (0.7)	4

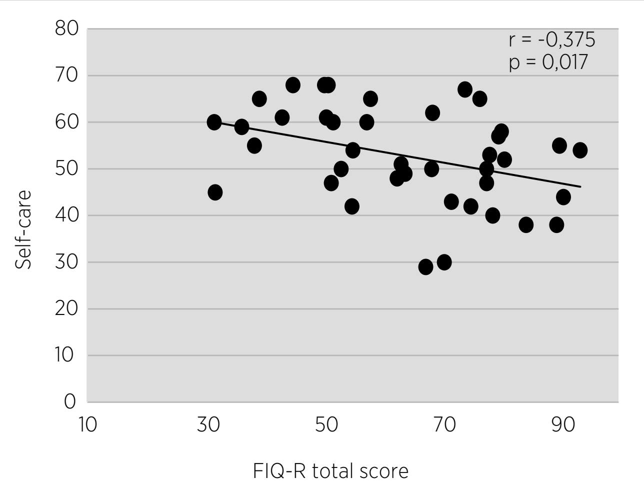
Table 3 describes the correlation between self-care and sociodemographic and clinical variables. A weak correlation was observed between self-care and social status and a weak negative correlation with total FIQ-R score – considering its domains of function, impact and symptoms.

Table 3. Correlation between self-care agency and sociodemographic and clinical variables

	r	p
Age	0.132	0.416
Marital status	0.08	0.62
Education	0.103	0.526
Social status	0.391	0.012*
Time since onset of disease	−0.155	0.338
WPI	−0.113	0.485
SS	−0.085	0.598
VAS	−0.187	0.246
FIQ-R	−0.375	0.017*
Function	−0.338	0.033*
Impact	−0.315	0.047*
Symptoms	−0.332	0.036*

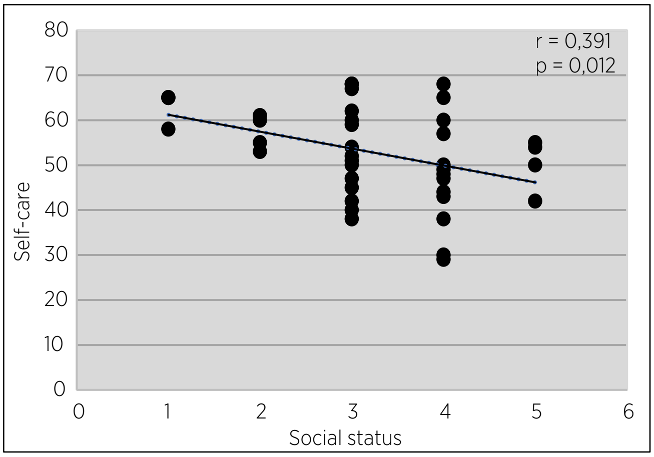
*Values with p<0.05; excellent correlation: r>0.75; moderate correlation: 0.40≤r<0.75; weak correlation: r<0.40.

Graph 1 shows data of the dispersion of self-care in relation to the FIQ-R, indicating that the lower the self-care level of an individual with FM, the worse the quality of life.



Graph 1. Dispersion of self-care in relation to the FIQ-R total score.

Graph 2 shows self-care scores in relation to the social status of each participant, indicating that the higher the social status, the lower the self-care level.



Graph 2. Dispersion of self-care in relation to social status

DISCUSSION

This study aimed to evaluate self-care agency of individuals with FM and its secondary objective was to check for associations of self-care with sociodemographic variables, symptoms and quality of life. The results show moderate self-care agency and a weak association between self-care and quality of life and social status in individuals with FM. In this sense, Sousa et al.[12] conducted in the United States a descriptive analysis of the Appraisal of Self-Care Agency Scale-Revised (ASAS-R) with the general population, which also reported moderate self-care agency, confirming the results of our study.

Self-care is a complementary determinant condition in the treatment of FM, as it promotes patient empowerment[14]. Marques, Assumpção and Matsutani[15] propose seven levels of help to individuals with FM; one of them is the transformation involving a change of focus, that is, the acceptance of changes in life habits and adoption of positive behaviors regarding FM.

Cedraschi et al.[16], who also emphasize the importance of developing the practice of self-care, conducted a study with individuals with FM to assess the effectiveness of a group-based multidisciplinary self-care program. The program combined education, promotion of self-care strategies, development of coping skills and physical activity. After six weeks, improvements were observed in the quality of life and pain of participants.

In our study, the ASAS-R items that showed lower values were: 'In general, I don't have the energy to take care of myself as I should' and 'I am not always able to take care of myself the way I want to,' suggesting individuals need to be encouraged to take care of themselves with more determination and accept changes in life habits. The lack of support and understanding of family members regarding their challenges and physical limitations due to the syndrome may be determinants for these findings, in agreement with the study conducted by Nicassio and Radojevic[17] that reported effective family support in health care programs for individuals with chronic pain.

The items in the self-care agency questionnaire that showed satisfactory results and more positive answers ('I agree' or 'I totally agree') were: 'If I take a new medication, I look for information about its side effects to take better care of myself,' 'I often take measures to ensure my safety and the safety of my family' and 'I am able to get the information I need when my health is threatened.' This finding indicates the participants are in an empowerment process by taking their own initiatives, promoting changes to leave old habits to improve health and, consequently, quality of life. On the other hand, regarding the classification of the questionnaire items based on its factor structure, Factor 1 – Having power to self-care was presented the highest frequency of answers, indicating the study participants have this ability.

Regarding symptoms, pain was moderate, without association with self-care, suggesting pain is not a factor that prevents patients from performing daily activities. A study by Scala et al.[18] suggested that most patients with chronic pain showed readiness to perform self-care practices and moderate pain.

The level of association between self-care and quality of life was low and suggested that the greater the empowerment capacity of individuals, the better the quality of life. However, the impact of FM on quality of life was severe, indicating that, due to the syndrome, the level of essential and supplementary conditions of humans can be deeply affected, generating instability in physical and psychological well-being, and such instability may promote considerable changes in an individual's habits, degree of independence and interpersonal relationships. A study by El Rabbat, Mahmoud and Gheita[19] proposed quality of life, measured by the FIQ-R, is worse among individuals with FM, when compared to non-FM individuals.

This study also showed that the higher the participant's social status, the lower the self-care level. This finding was not expected, since individuals with higher purchasing power have more access to information and more resources to promote self-care, which would suggest better support in daily life.

Then, this study has a limitation, which refers to a lack of studies and instruments assessing self-care in FM in the literature, not allowing data comparison. Therefore, further studies must be conducted to analyze this topic.

CONCLUSION

This study reports moderate self-care agency and a weak association between self-care and quality of life and social status. Therefore, further studies should be conducted to assess self-care agency of individuals with FM to provide a better understand the self-care meaning for these patients.

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