



## Review article

# Psychological aspects of juvenile fibromyalgia syndrome: a literature review<sup>☆</sup>



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## ABSTRACT

Juvenile fibromyalgia syndrome (JFMS) is a non-inflammatory chronic pain condition that occurs mainly in girls aged 9–15 years. JFMS is characterized by constant widespread pain in different parts of the body, poor sleep quality, daytime sleepiness and an altered mood. Concomitant psychological and organic factors result in a diminished capacity to cope with pain. The quality of life of individuals with chronic pain and their caregivers is severely restricted and the occurrence of symptoms of anxiety and depression is common in this population. The aim of the present study was to perform a systematic review of the literature on psychosocial factors related to JFMS. The findings reveal differences in opinion between patients and family members regarding the effect of the condition, as mothers tend to classify JFMS as more severe than the patients themselves. Individuals with JFMS seem to share the same personality traits and there seems to be a type of family environment that is favorable to the occurrence of this condition. Psychological and functional aspects should be treated with methods that can help patients and family members alter their coping strategies regarding day-to-day problems, attenuate the dysfunctional consequences of pain and fatigue and diminish the risk of catastrophizing that individuals submitted to constant pain develop in relation to their surrounding environment.

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## Aspectos psicológicos da síndrome da fibromialgia juvenil: revisão de literatura

### RESUMO

**Palavras-chave:**  
Fibromialgia  
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A síndrome da fibromialgia juvenil (SFJ) é uma condição dolorosa não inflamatória crônica que ocorre principalmente em meninas com idades entre 9 e 15 anos, podendo ser caracterizada por dores generalizadas e constantes em várias regiões do corpo, distúrbios do sono, fadiga diurna e estado de humor alterado. Fatores psicológicos e biológicos concomitantes resultaram na diminuição da capacidade de lidar com a dor. A qualidade de vida das crianças que sofrem de dores crônicas, e a de seus cuidadores, é severamente prejudicada, e a ocorrência de sintomas de ansiedade e depressão é mais comum nessa população. Este estudo objetivou realizar uma revisão sistemática da literatura dos fatores psicossociais relacionados com a SFJ. Os achados revelam uma percepção divergente entre pacientes e familiares em relação aos efeitos da condição, sendo que as mães dos pacientes tendem a classificar a doença com uma gravidade maior que os próprios pacientes. Os pacientes com fibromialgia parecem compartilhar os mesmos traços de personalidade, e parece existir um tipo de ambiente familiar favorável à ocorrência da doença. As implicações psicológicas e funcionais devem ser tratadas com métodos que ajudem pacientes e familiares a modificar suas estratégias de enfrentamento dos problemas cotidianos, a aliviar as consequências disfuncionais da dor e da fadiga e a diminuir o risco de catastrofização.

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### Introduction

Fibromyalgia in children and adolescents is a non-inflammatory chronic pain condition that mainly occurs in girls aged nine to 15 years<sup>1</sup> and is therefore denominated juvenile fibromyalgia syndrome (JFMS). This syndrome is relatively under-investigated, but is characterized by constant widespread pain in different parts of the body, poor sleep quality, daytime sleepiness and an altered mood. Despite the similarities between JFMS and fibromyalgia in adulthood, the reduction in physical activity, absenteeism from school and the less-developed coping mechanisms in youths justify the differentiated analysis of JFMS.<sup>2-5</sup> The quality of life of individuals with chronic pain and their caregivers is severely restricted and the occurrence of symptoms of anxiety and depression is common in this population.<sup>6</sup>

The aim of the present study was to perform a systematic review of the literature on psychosocial factors related to JFMS. Searches were performed in the PubMed, Scielo, LILACS and MEDLINE databases using the keywords "fibromyalgia", "child", "juvenile", "primary fibromyalgia" and "syndrome" as well as Boolean operators. Articles published in English, Portuguese and Spanish between 1985 and 2014 on descriptive characteristics or factors associated with JFMS were selected. The initial search led to the retrieval of 108 records. Following the exclusion of editorials, letters to the editor, abstracts from conferences, review articles on other topics, articles on fibromyalgia in adults and articles focused on diagnostic tools rather than patients, 54 papers were selected. Twelve more articles were excluded because the focus was on treatment without taking into consideration the psychosocial characteristics of the subjects. Thus, 42

pediatric references and seven complementary texts were analyzed.

### Prevalence and etiology

The diagnosis of JFMS remains the subject of debate with regard to what criteria to use<sup>1,6,7</sup> (specifically, those of the American College of Rheumatology<sup>8</sup> (ACR) or those proposed by Yunus and Masi<sup>9</sup>), the measurement of the force to be applied in the evaluation of tender points,<sup>6,7,9-11</sup> the definition of headache<sup>7</sup> and the most adequate assessment tools for the determination of anxiety and depression. One systematic review from Germany<sup>7</sup> proposes that even the term "juvenile fibromyalgia syndrome" should be discarded due to the lack of diagnostic consistency. Such methodological difficulties partially explain the differences in prevalence rates across studies, which range from 1%<sup>8</sup> to 6%.<sup>4</sup>

There are no conclusive studies on the possible causes and risk factors of JFMS and speculations regarding associated genetic and metabolic factors lack adequate scientific evidence. Some studies have sought to demonstrate the occurrence of hormonal abnormalities in individuals with fibromyalgia,<sup>12,13</sup> but not specifically in young patients. Buskila and Neumann,<sup>14</sup> and Feng et al.<sup>15</sup> have identified candidate genes for the development of fibromyalgia, but concomitant environmental and familial factors hinder drawing definitive conclusions regarding the determination of the syndrome. However, this notion should not be discarded, as the literature has demonstrated low levels of growth hormone<sup>16</sup> as well as the occurrence of hypermobility syndrome<sup>17</sup> in patients with JFMS, both of which have a genetic origin. What can be stated with some degree of certainty is that JFMS occurs together with familial conditions that have not yet been

genetically proven. Relatives of individuals with JFMS report a greater degree of fatigue<sup>18</sup> and have poor sleep quality. Moreover, studying a group of 35 individuals with JFMS, Roizenblatt et al.<sup>19</sup> found that 71% of the mothers also had fibromyalgia.

## Characteristics

There is debate in the literature regarding whether JFMS is an independent syndrome or the juvenile version of fibromyalgia found in adults.<sup>2,6,7,20–22</sup> Buslika et al.<sup>4</sup> reported the spontaneous remission of symptoms in 73% of patients evaluated after a 30-month follow up. Mikkellson<sup>3</sup> report that the syndrome persisted in only 26% of the patients evaluated at a one-year follow up. Both studies give an indication that the manifestation of JFMS differs from adult fibromyalgia, which does not generally go into remission,<sup>23</sup> although treated patients often experience a significant improvement in function. In a case series study, the authors found that patients with JFMS who abandoned treatment were the oldest individuals in the sample and had characteristics similar to the adult manifestation of fibromyalgia, thereby differing from the cases that remained in treatment.<sup>24</sup> A number of authors report differences between adults and youths, such as a gradation of symptoms or as the result of long periods without treatment on the part of adults who suffered widespread pain in childhood and adolescence.<sup>5,6,25,26</sup> Thus, the early detection of JFMS is an indication of a better prognosis,<sup>2</sup> with significant gains in quality of life<sup>20</sup> and functionality for individuals who receive adequate treatment, whereas those with widespread pain that are not treated adequately have a greater chance of developing fibromyalgia.<sup>21</sup>

An altered sleep pattern seems to be a common factor among patients with JFMS. In a study with a one-year follow up, Mikkelsen<sup>3</sup> found that all individuals analyzed had trouble sleeping. In a study conducted in Brazil, the authors found that 43% of the patients in the sample could not achieve restorative sleep.<sup>27</sup> The authors of another study<sup>28</sup> found poor sleep quality among both individuals with JFMS and their parents.<sup>29</sup> In a study involving polysomnography for the evaluation of sleep quality among patients with JFMS, the authors found that the subjects had trouble falling asleep, a reduced total sleep time, non-restorative sleep and greater periods of awakening throughout the night; moreover, 42% of the sample exhibited excessive limb movements during sleep.

Kashikar-Zuck et al.<sup>1</sup> proposed a conceptual model for the understanding of JFMS, the central factors of which are an altered perception of pain and the notion that fibromyalgia is characterized by concomitant psychological and organic factors resulting in a diminished capacity to cope with pain. This differentiates the syndrome from psychosomatic disorders, as the pattern of pain expression in fibromyalgia is relatively constant and persistent, whereas psychosomatic pain tends to be less constant.

## Psychological aspects of JFMS

Individuals with JFMS have a poorer quality of life<sup>30</sup> as well as more symptoms of depression<sup>5,24,25,31</sup> and anxiety<sup>24,25,32</sup> than youths with other types of chronic pain<sup>33</sup> and control

subjects, which results in a greater occurrence of disease-related dysfunctional behavior and disability,<sup>34</sup> greater absenteeism from school and more visits to healthcare services.<sup>27</sup> One study found that 12% of parents opt for home schooling due to the frequent pain their children face, whereas only 2% of the general population of the United States choose this option; moreover, the mean number of absences from school totals 41 days yearly among individuals with JFMS versus nine days yearly among the general population.<sup>35</sup>

The discussion on the origins of JFMS needs to lead to the clarification of the relationship between physiological and psychological aspects. A number of authors have sought to characterize JFMS regarding these aspects, but few studies offer a greater understanding of the causes and consequences of the aggravating psychological comorbidities found in youths who suffer from widespread pain. Regarding the influence of family in the development of JFMS, studies report concomitant symptoms in parents and children with fibromyalgia.<sup>19,22,36,37</sup> For instance, a recent study on widespread pain among youths found a greater number of parents with pain, fibromyalgia and mental problems.<sup>26</sup> However, no study has yet established the relationship of causality.

Despite the evidence of genetic factors, the influence of parents on the learned behavior of children is widely recognized and may be associated with poor functional reactions to pain, thereby contributing to the development of factors that contribute to the diagnosis of JFMS, such as anxiety and depression. For instance, the similar sleep pattern<sup>19,27</sup> among patients and relatives may be influenced by social aspects or cohabitation conditions that have not been evaluated in studies involving polysomnography.<sup>27,28</sup>

According to some studies, youths with fibromyalgia seem to come from families that are more anxious and disorganized,<sup>36,38</sup> which may exert an influence on coping with day-to-day problems. Moreover, the parents of such children have more pain and poorer emotional relationships<sup>37</sup> and tend to use healthcare services more. Other examples of the environmental influence on the development of behavioral patterns among youths with fibromyalgia are found in how these individuals react to factors that either trigger pain or result from pain. A study on coping strategies in adverse situations found that youths with JFMS use more problem-focused avoidance strategies than a control group and the same coping pattern was found among the parents of these children.<sup>18</sup> Sil et al.<sup>39</sup> conducted a study on the influence of the familial environment on the development of JFMS and concluded that a high degree of parental control can also lead to a higher degree of depression among these youths without exerting an influence on physical health. This seems to be plausible, as highly controlled environments lead to greater feelings of helplessness and, consequently, depression.

Differences in opinion are found between patients and family members regarding the effect of the JFMS,<sup>22</sup> as mothers tend to classify JFMS as more severe than the patients themselves<sup>37</sup> and affected youths act more effectively than adults with regard to diminishing pain.<sup>34</sup> Libby and Glenwick<sup>40</sup> found that individuals with JFMS suffer more from day-to-day annoyances than the symptoms of the syndrome or stressful events and family support seems to be a protective factor against the exacerbation of the condition. Moreover, the

temperament of affected individuals in daily living results in more behavioral problems than those found in healthy controls.<sup>36</sup> It therefore seems that individuals with JFMS spend a considerable amount of energy in coping with the symptoms of the syndrome, which gives them a social disadvantage in comparison to others.

Adults<sup>41</sup> and youths<sup>34,42</sup> with fibromyalgia seem to share the same personality traits and dysfunctional problem-coping strategies. Moreover, there seems to be a familial environment that is favorable to the occurrence of this condition. Therefore, one may speculate that, although fibromyalgia may not have a psychological origin, it causes a reduction in the functional quality of life of affected individuals,<sup>18</sup> which may be a common factor to the development and exacerbation of the syndrome.

## Management

There is consensus in the literature that treatment for fibromyalgia should be multidisciplinary<sup>1,2,6</sup> and focused on non-pharmacological interventions, with the use of medication only for the control of symptoms and comorbidities.<sup>7</sup> Treatment should involve physical therapy,<sup>32</sup> exercise<sup>43</sup> and psychotherapy.<sup>44,45</sup> Behavioral interventions are also effective<sup>33</sup> and parental education regarding the symptoms of JFMS favors an early diagnosis.<sup>46</sup>

While it is not yet possible to determine which psychological approaches are the most effective, Kashikar-Zuck et al. have successfully employed cognitive-behavioral therapy for the treatment of patients<sup>46</sup> with JFMS and the same group of researchers demonstrated functional improvement in such patients in a randomized trial, but without a follow-up evaluation to determine the long-term effects of therapy.<sup>47,48</sup> He describes the clinical practice of cognitive-behavioral therapy as training the patient in muscle relaxation and distraction techniques, activity pacing, and cognitive strategies to reduce distress and encourage active coping, this approach lead to a reduction in distress and disability.

However, when the aim of cognitive-behavioral therapy was to increase the level of physical activity among youths with JFMS, this approach proved less effective than educational interventions and neither approach improved patient adherence to such activities.<sup>49</sup> Another study that employed cognitive-behavioral therapy for the treatment of pain obtained moderate results in the post-intervention and follow-up evaluations.<sup>24</sup> However, the study cited had methodological problems, such as the heterogeneity in the age of the sample, which ranged from eight to 18 years and the older patients were the ones who abandoned treatment.

## Conclusions

After the present review of the literature, the determination of whether JFMS is a differentiated condition from fibromyalgia in adulthood remains undefined, as researchers have offered evidence favorable to both positions. From the standpoint of personality traits, similarities are found in the

dysfunctional way adults and youths with fibromyalgia cope with daily problems and in the altered perception of pain. However, the perception of the severity of the condition indicates an important difference, as youths tend to characterize their condition as less severe and cope with the symptoms better.

One way to demonstrate the possible gradation of JFMS compatible with age would be the development of studies that differentiate younger and adolescent patients. The same logic applies to the forms of treatment, as most studies published thus far address treatment in a limited fashion and have not reached conclusive results. Moreover, cohort studies and clinical trials on JFMS are needed.

While fibromyalgia is not classified as a psychiatric disorder, its psychological and functional aspects should be treated with seriousness and psychological methods should be employed that can help patients and family members alter their coping strategies with regard to day-to-day problems, attenuate the dysfunctional consequences of pain and fatigue and diminish the risk of catastrophizing that individuals submitted to constant pain develop in relation to their surrounding environment. Thus, an individualized psychological evaluation of patients with JFMS is essential to the definition of the most adequate form of therapy, as there is little evidence regarding the best psychological approach in these cases and only cognitive-behavioral therapy is cited in the literature.

## Conflicts of interest

The authors declare no conflicts of interest.

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