EDITORIAL

Childhood and adolescence lost in juvenile fibromyalgia: a close look at functionality

Infância e adolescência perdidas na fibromialgia juvenil: um olhar atento para a funcionalidade

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Juvenile fibromyalgia (JFM) is a chronic condition of non-inflammatory origin, characterized mainly by diffuse, migratory musculoskeletal pain of moderate to severe intensity[1-3]. Other symptoms may be associated with fatigue, sleep disturbance, mood swings, cognitive dysfunction and somatic manifestations such as headache, irritable bowel and dysautonomia[4].

It affects children and adolescents of all ages, with an average age of onset of symptoms of 11 to 13 years. The time elapsed from the onset of symptoms to diagnosis is often long, with an average ranging from 18 to 32 months being the longest time in children who start symptoms under the age of 10 years, suggesting greater underdiagnosis in younger children[2,5]. The time of coexistence with the symptoms without diagnostic elucidation can compromise the timely treatment, causing limitation of the essential activity for children and adolescents that is playing.

The difficulty in diagnosis may occur due to late identification of other medical specialties and consequent delay in referral to a pediatric rheumatologist; attribution of other common childhood diagnoses, such as growing pain; barriers to access to pediatric rheumatologist; devaluation of the symptoms reported by the children; and variability of the diagnostic criteria used[2,5-7]. The trip to several medical specialties in search of a diagnosis generates high costs, feelings of distress and anguish, and delays the beginning of treatment directed to the multiple demands that a complex syndrome requires[3,6].

Estimated prevalence data range from 1.2% to 6.2%, with predominance in females and whites[1,8,9]. The diagnosis is clinical, based on the patient's history, physical examination and the diagnostic criteria established in the literature[3]. Most young people with JFM continue to present symptoms in adulthood and a part of them meet the ACR criteria for fibromyalgia in adults[10,11]. Symptoms may, isolated or associated, and at different levels of severity, contribute to reduced functionality and impaired quality of life.

Functionality, according to the International Classification of Functioning, Disability and Health (ICF) is the dynamic interaction between health status (body structure and functions, activity and participation) and contextual factors (environmental and personal factors). The ICF was created by the World Health Organization in 2001, and is an instrument that aims to enable the recognition of the conditions of functionality in an individualized way, from the identification of environmental and personal factors[12].

In this context, JFM, as a health condition, encompasses a diversity of symptoms triggered by changes in function and structure; limitation of activities of daily living, learning, mobility; and restriction on school participation, recreation and leisure activities, and interpersonal relationships. Regarding environmental factors, family environment, support and attitudes of family members, colleagues and health professionals and access to health services are related to different levels of disability, as well as personal factors, represented by beliefs, attitudes, ways of coping, catastrophization and kinesiophobia.

In JFM, evidence relates psychosocial factors; pain, sleep and fatigue; parental history and family environment; family and peer relationships; and coping behavior and catastrophization, with higher levels of disability[11,13-15].

Higher levels of depressive symptoms are related to higher rates of school absenteeism[16], in addition to the presence of greater anxiety symptoms and worse physical performance[10,11]. Chronic pain, fatigue, non-restorative sleep, depressive symptoms and functional disability are prevalent in this population[2]. Symptomatology at high levels of severity contributes to decreased school attendance, restriction of activities of daily living, sports, leisure and difficulty concentrating, paying attention and memory.

History of chronic pain and maternal depressive symptoms are associated with greater functional impairment and the family environment confers a higher risk of disability[16,17]. Controlling family environment is associated with higher levels of depressive symptoms of adolescents, which hinders the development of autonomy and independence of the same in the self-management of the disease[15]. Worse coping strategies and higher catastrophizing pain are associated with higher levels of depressive symptoms[14]. Such facts can be explained by social learning, which reflects the reproduction of the parental behavior model in coping with pain, since children initially learn strategies and behaviors through the first relationships experienced.

The functional disability in children and adolescents with JFM causes restriction to play, which is essential for the physical, social, emotional and cognitive development[18]. The restriction generates a high impact on families and compromises the milestones of the child's overall development, well-being and quality of life. Child development is an ongoing process that begins

in relationships with parents and then with caregivers, health professionals and other children. The child develops motor, cognitive, social and emotional skills when playing and exploring toys, games and experiences.

The damages of functional disability in childhood constitute risk factors for economic, social, psychological, physical and marital problems in adult life[11]. Adolescents with JFM have greater difficulty in entering college, in the job market, are more likely to be financially dependent on benefits or family members and emotionally support to manage life[10,11]. The restriction of the possibilities of play due to the symptoms, limitation of mobility activities and restriction of social participation has a negative impact on adult life with a greater propensity to physical inactivity, social isolation, depression and on the low capacity to solve problems and cope with the disease.

The understanding of the repercussions of decreased functionality in childhood and the biopsychosocial model reinforce the importance of a multiprofessional evaluation, with attention to all aspects involved and targeted multimodal treatment, focusing on reducing activity limitations, reducing restrictions on social participation and consequently improving the quality of life of these children. A close look at this population and appreciation of the reported symptoms are essential for early diagnostic elucidation and treatment that enable play, leisure and sport guaranteed by law as a right of every child and adolescent. Public policies that guarantee access to health services, permanent education in primary care, investment in technological innovation research to support diagnosis and education of the population about JFM They are strategies to broaden this view in defense of childhood and adolescence.

Josimari Melo DeSantana[1]
[1]Universidade Federal de Sergipe, Departamento de Fisioterapia, Programa de Pós-Graduação em Ciências Fisiológicas, Programa de Pós-Graduação em Ciências da Saúde, Aracaju, SE, Brasil
https://orcid.org/0000-0003-1432-0737
E-mail: josimelo@academico.ufs.br
Tainã Ribeiro Klinger Florêncio[2]
[2]Universidade Federal de Sergipe, Departamento de Fisioterapia, Programa de Pós-Graduação em Ciências da Saúde, Aracaju, SE, Brasil
https://orcid.org/0000-0002-2165-1334
E-mail: tainaklinger@academico.ufs.br

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