

## Actigraphy-Based Physical Activity Monitoring in Adolescents With Juvenile Primary Fibromyalgia Syndrome

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**Abstract:** Juvenile primary fibromyalgia syndrome (JPFS) is a chronic pain condition associated with significant impairment in physical functioning, but no studies have used newer technologies such as actigraphy to document objective physical activity levels in JPFS. This is the first study to objectively describe physical activity in JPFS patients and examine the relationship of pain, perceived functional impairment, and depressive symptoms on physical activity. One hundred four clinically referred adolescents with JPFS (ages 11 to 18 years) wore a hip-mounted actigraph for 1 week. Data on pain intensity, functional disability, depressive symptoms, and psychiatric diagnoses were obtained using self- and parent-report measures and a standardized psychiatric interview. Results showed that younger patients were more active. Pain intensity was not significantly associated with physical activity levels overall, but the most highly active group of adolescents reported lower levels of pain and disability than the least active. Parent report of adolescents' physical functioning and depressive symptoms were significantly correlated with adolescents' physical activity levels. Actigraphy provides a unique source of information about physical functioning which is distinct from adolescents' self-report of physical functioning in JPFS. Preliminary findings suggest that further study of factors that predict perceived and actual physical functioning in JPFS is warranted.

**Perspective:** This study presents the results of physical activity monitoring in adolescents with JPFS using actigraphy. Results indicate that actigraphy provides a unique source of objective information that can advance our understanding of physical disability in JPFS and the factors associated with physical impairment.

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**Key words:** Juvenile fibromyalgia, actigraphy, pediatric pain, physical functioning, depression.

Received July 17, 2009; Revised November 25, 2009; Accepted December 13, 2009.

Supported by a grant from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS Grant No. R01 AR050028).

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1526-5900/\$36.00

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doi:10.1016/j.jpain.2009.12.009

Juvenile primary fibromyalgia syndrome (JPFS) is a pediatric chronic pain condition typically first diagnosed in the early adolescent years, and affecting mostly girls.<sup>35</sup> Symptoms of JPFS include widespread musculoskeletal pain, multiple painful tender points, disrupted sleep, chronic fatigue, and other associated features.<sup>35</sup> Chronic pain conditions such as JPFS can affect numerous domains of functioning including physical,<sup>16,33</sup> social,<sup>17</sup> and

psychological functioning.<sup>1,14,20</sup> Assessments of physical and psychosocial functioning in JPFS, as in most studies of chronic pain, have relied almost exclusively on self-report.<sup>7,19</sup> Two published comprehensive reviews found that studies measuring pain-related disability, including physical functioning, relied solely on self-report and to a lesser extent, parent- or teacher-report.<sup>8,9</sup> Although the experience of pain is by definition a subjective experience, the impact of pain on physical function has both subjective (ie, perceived ability to engage in activity) and objective (ie, actual engagement in activity) components. Yet, objective physical functioning in patients with JPFS has not been documented.

Use of objective methods, such as actigraphy, to assess physical functioning is important for at least 2 reasons. First, it is unknown whether self-report instruments reliably reflect the impact of pain on physical functioning because adolescents' self-report of physical functioning may be inconsistent with actual activity. This could be due to retrospective recall bias,<sup>31,32</sup> social-desirability bias,<sup>30</sup> or an inaccurate understanding of what constitutes levels of activity (eg, reporting "shopping at the mall" as a vigorous activity). Second, it is observed that some JPFS patients remain vigorously active despite significant pain, and more research is needed to understand the factors that are associated with their ability to maintain high levels of activity.

Three published studies have demonstrated the utility of actigraphic measurement in individuals with chronic pain. The first study examined physical activity in 22 adult fibromyalgia (FMS) patients, 9 patients with depression and 28 healthy control subjects.<sup>23</sup> Results showed that FMS patients with comorbid depression demonstrated significantly lower daytime activity as compared with those with FMS only and control subjects. The second study compared physical activity between 29 adult FMS patients, 9 patients with chronic fatigue syndrome (CFS), and 27 healthy control subjects.<sup>22</sup> Results indicated that FMS and CFS patients had lower levels of vigorous physical activity and that higher levels of pain and fatigue were associated with lower physical activity. In the third study, physical activity levels were compared between 20 adolescents with pain conditions such as chronic head/neck pain, limb pain, back pain, and so forth (but not specifically JPFS) and 20 healthy control subjects.<sup>25</sup> Results demonstrated that adolescents with chronic pain had greater activity limitations than control subjects and spent significantly less time in moderate and vigorous activity. Higher activity levels were associated with younger age, lower pain ratings, and fewer depressive symptoms. The current study sought to extend the findings from these early studies by examining physical activity in a relatively large sample of adolescent patients with JPFS.

The specific aims of this study were to (1) describe physical activity levels in adolescents with JPFS, (2) examine differences between high-active and low-active adolescents in terms of age, pain intensity, depressive symptoms, and functional impairment, and (3) explore the impact of psychiatric disorders on physical activity. It was hypothesized that the most active adolescents would be younger and would have lower levels of

pain, depressive symptoms and functional impairment, compared with the least active adolescents. It was expected that those who met criteria for a depressive disorder diagnosis would show significantly lower vigorous activity levels. Results of a portion of this study were previously published in abstract form.<sup>11</sup>

## Materials and Methods

### Participants

Participants were 104 adolescents between the ages of 11 and 18 years with JPFS (89.4% female) who were screened for a larger ongoing clinical trial on behavioral treatment for juvenile fibromyalgia and their parents. A description of a subset ( $n = 76$ ) of this JPFS sample was previously published in a study of psychiatric comorbidities in adolescents diagnosed with JPFS.<sup>18</sup> Adolescent patients were recruited from 4 pediatric rheumatology clinics from hospitals in the Ohio and Kentucky region and the study was approved by each hospital's institutional review board. All participants met Yunus and Masi criteria<sup>35</sup> for JPFS classification, including generalized musculoskeletal aching for greater than 3 months, the presence of at least 5 of 18 tender points, and at least 3 associated symptoms such as poor sleep quality, fatigue, chronic anxiety, irritable bowel syndrome, or chronic headaches. Exclusion criteria included individuals with other chronic rheumatic diseases such as juvenile idiopathic arthritis or systemic lupus erythematosus, individuals with a documented developmental delay or impairment such as autism, cerebral palsy or mental retardation, and those known to be taking opioid medications for the treatment of fibromyalgia pain. Participants were excluded if they were taking opioid medications due to the requirement in the larger clinical trial for patients to be receiving "usual medical care" for JPFS.

### Procedure

Eligible participants were introduced to the study by their primary rheumatologist. If they were interested in participating, they were contacted by the research assistant to provide a detailed description of the study. Written informed consent was obtained from parents and written and verbal assent were obtained from adolescents before study participation. Measures in this study were administered as part of the comprehensive screening for the larger clinical trial. Once the evaluation was scheduled, a research assistant mailed daily pain diaries and an actigraph<sup>15</sup> to the patients' homes. They were instructed to begin keeping daily pain diaries and to wear the hip-mounted actigraph at all times (except while showering or bathing) for 1 full week before the evaluation visit at the clinic. Participants were asked to return the daily diaries and actigraph at the study visit. During the evaluation, parent/s and adolescents completed questionnaires separately, and a trained doctoral level psychologist or psychology fellow conducted a standardized psychiatric interview with the parent/s and adolescent together. Upon completion, participants were

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