ABSTRACT

Prevalence of chronic pain in Duchenne muscular dystrophy patients in non-ambulatory stage

Introduction: Chronic pain is a frequent symptom in patients with Duchenne muscular dystrophy (DMD) as reported, in up to 73%, affecting their normal activities, participation and quality of life; however it is an underdiagnosed symptom, and therefore, undertreated. **Objective:** To establish the prevalence of chronic pain in a population with non-ambulatory DMD attending Instituto Teletón Santiago (ITS). **Materials and methods:** Descriptive, cross-sectional study in DMD patients of Instituto Teletón Santiago, of 12 years old and older, who were in an early or late non-ambulatory stage. By means of a questionnaire designed by the authors, adapted from 'Brief Pain Inventory' and 'ID-Pain', and administered via telephone, it was possible to obtain data on the presence of acute, chronic pain and its intensity, frequency, location, clinical characteristics and interference with daily life activities and the use of analgesic drugs. Data collected helped to do an estimation of the prevalence of pain in the last week, chronic pain as well as summary measures for location, intensity and clinical characteristics. **Results:** Of 74 active patients with DMD and in compliance with the inclusion criteria, 23 subjects responded the questionnaire (31% response rate); average age was 18.3 years, and 9 months since loss of walking ability; prevalence of acute pain was 13% and 13% for chronic pain; most common localization was in the hips, followed by neck, spine and lower limbs; duration and frequency were variable and of moderate intensity. **Conclusion:** Pain has a lower prevalence in the studied population compared to the literature, however, it affects multiple locations and has an impact on their daily activities, and therefore it is important to record the presence of chronic pain in clinical practice. It is necessary to get a higher response rate in future studies and quantify pain with an instrument developed especially for this population.

Key words: Duchenne muscular dystrophy; pain, teenagers, adults, adolescents.