Pain and activity limitations in children with Duchenne or Becker muscular dystrophy.

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Abstract
The purpose of this study was to examine the prevalence and characteristics of pain in children with Duchenne (DMD) or Becker (BMD) muscular dystrophy, including the nature of disagreements concerning pain symptoms among children, parents, and physicians, and limitations in daily activities. Male children (age 8-18 y, n=53) and parents (n=53) completed questionnaires assessing pain intensity (visual analogue scale), pain frequency (Likert scale [LS]), pain duration (LS), emotional distress due to pain (LS), and pain location (body outline markings). The Child Activity Limitations Interview was also completed by both raters to assess daily activities that are limited by recurrent pain. Physicians completed a form indicating medical history and pain symptoms. The majority of children with DMD (mean age 13 y 11 mo [SD 3.38]; range 8-18 y) or BMD (mean 14 y 10 mo [SD 1.48]; range 12-17 y) were non-ambulatory (79 and 50% respectively) and experienced pain according to self (54-80%) and parent reports (70-90%). Pain typically occurred at least once per week and was of mild to moderate intensity. Most children experienced pain for less than a few hours and little to moderate levels of emotional distress due to pain. Pain occurred in the lower back, spine, and legs, and was described as 'aching'. Children and parents indicated significantly more intense pain than the physician. Actual agreement between parent and child report on pain symptoms was poor to fair. Pain is a common occurrence in children with DMD or BMD, yet may be under-recognized. Pain assessment needs to be a standard part of care and may identify difficulties faced by these children to be targeted by interventions.

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