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Pain in adolescents with spinal muscular atrophy and Duchenne and Becker muscular dystrophy.

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Abstract

BACKGROUND/PURPOSE: The purpose of this study was to explore the prevalence, nature and scope of pain in adolescents with spinal muscular atrophy and Duchenne and Becker muscular dystrophy and whether the pain differs between diagnostic groups or between adolescents with different ambulation status. Furthermore to study the consequences of pain and to identify pain-exacerbating and pain-relieving factors.

METHODS: In a national survey, fifty-five adolescents with spinal muscular atrophy and dystrophinopathy completed a questionnaire assessing pain frequency, duration, location using a body map, intensity and discomfort using visual analogue scales, pain interference using a modified version of Brief Pain Inventory and factors exacerbating and relieving pain.

RESULTS: Sixty-nine per cent of the adolescents reported pain during the past three months and 50% reported chronic pain. The pain prevalence did not differ significantly between diagnostic groups or between ambulators and non-ambulators. The average pain intensity was graded as mild and the worst pain as moderate. The pain typically occurred weekly, most frequently in the neck/back or legs. General activity and mood were the areas that were most affected by pain. Common pain-exacerbating factors were sitting, too much movement/activity and being lifted or transferred.

CONCLUSION: Pain is a frequent problem in adolescents with spinal muscular atrophy and dystrophinopathy. The assessments used enable an understanding both of the nature and scope of pain and of the impact of pain in everyday life. The study highlights the importance of assessing pain in a systematic manner and offering an individual approach to interventions designed to reduce pain in this population.

KEYWORDS: Adolescent; Becker muscular dystrophy; Duchenne muscular dystrophy; Neuromuscular disorders; Pain; Spinal muscular atrophy

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