Pain in hereditary neuromuscular disorders and myasthenia gravis: a national survey of frequency, characteristics, and impact.

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Abstract
The aim of our study was to evaluate pain frequency, intensity, and disability levels in a population with neuromuscular disorders (NMD). Of 862 questionnaires mailed to outpatients treated at 10 centers, 511 (300 men and 211 women) responded with answers suitable for analysis (response rate: 59.3%). Patients had Duchenne or Becker muscular dystrophy, type 1 myotonic muscular dystrophy, facioscapulohumeral muscular dystrophy, metabolic myopathy, or myasthenia gravis (MYA). The questionnaire packet included numeric scales for pain intensity and relief, the Brief Pain Inventory, the Saint Antoine Pain Questionnaire, and a scale to assess disability. More than two-thirds of the 331 patients (67.3%) suffered pain during the last three months. The mean number of days with pain was 18.4+/−15.1 days. The mean pain intensity was 4.8+/−2.5. Pain was usually diffuse (153 patients, 44%) and intermittent (228, 71%). Pain intensity varied by the NMD diagnosis; the most severe pain was observed in metabolic myopathy (13/27 patients suffered severe pain, 49%) and in MYA (16/42, 38%). Approximately three-quarters of patients had fewer than 10 days of inactivity due to pain during the last three months, and 98% had fewer than 30 days. Our study indicates that pain is frequent in hereditary muscle disorders and MYA. Mean intensity is moderate. Pain in NMD patients should be systematically assessed.

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