

# Chronic Pain Arise From an Initial and no Clear Cause

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## Abstract

Although the qualitative nature of our methodology and lack of a control group limit the extent to which conclusions can be firmly drawn, our data nevertheless clearly indicate that chronic pain is a significant problem for youths with neuromuscular diseases. The next step would be multi-centred studies done with larger numbers of children, each focusing on a single neuromuscular disease, rather than a diverse mixture of diseases such as was done in this study. Separating out studies into single-disease entities would allow investigators to compare the experiences of children with differing disorders, both myopathic and neuropathic. This would hopefully permit the formulation of better, more specific diagnostic tools and ultimately facilitate the development of effective treatment paradigms.

**Keywords:** Paradigms; Neuropath; Neuromuscular diseases; Relationships; Pain characteristics; Chronic pain

## Introduction

Challenges include dealing with the progressive nature of the vast majority of neuromuscular diseases, which creates a moving target for clinicians trying to provide effective treatment. Thus, future studies would optimally be prospective and longitudinal [1]. This would help best determine the complex interrelationships between chronic pain, physical disability, sleep and mood disorders, and family and interpersonal relationships in persons with NMDs across the lifespan. In the meantime, our current study, as well as other studies cited herein, provide ample evidence that youths and adults with neuromuscular diseases do experience significant problems with pain that negatively affect almost every aspect of their lives [2]. Clinicians caring for this patient population need to begin more effectively addressing these issues, perhaps first and foremost by simply inquiring about the nature and extent of pain in the patient with neuromuscular disease, the nature and extent of their pain. Given the findings in our study, optimal treatment would likely be multimodal, involving not only pharmaceutical agents but also physical rehabilitation and psychosocial interventions. In general, the frequency and intensity of pain reported in adults with NMD is significantly greater than levels of pain reported by the general US population and comparable to pain reported by adults with osteoarthritis and chronic low back pain. Recently there has been increasing attention and resources directed towards recognizing, understanding, and managing chronic pain in children with neuromuscular disease. Zebracki and Drotar recently examined the prevalence and characteristics of pain in children with Duchenne muscular dystrophy and Becker muscular dystrophy, including exploring any disagreements regarding pain symptoms among children, parents, and physicians. Their data showed that the majority of boys with DMD/BMD reported experiencing pain. Parental reports of pain were higher.

## Discussion

Pain typically occurred in the lower back, spine, and legs, and was described as aching. Both children and parents indicated significantly more intense pain than the physician. This study indicates that pain is not only common in boys with DMD/BMD but is also under recognized by treating physicians. This is consistent with the frequency of pain reported in other disabling childhood disorders, including cerebral palsy, where the experience of pain continues into the adult years as well. The extent and nature of pain in other forms of childhood neuromuscular disease has not been well studied. The purpose of this

study was to explore the nature and scope of chronic pain in a sample of youths with neuromuscular disease. Secondary aims included gaining specific knowledge about the nature of pain, including defining the pain frequency, pain intensity, pain location, pain quality, pain interference with function and quality of life, and pain interventions and their effectiveness [3]. All youths who met the study criteria were invited to participate in this study. The study was approved by the Institutional Review Board of Children's Hospital and Regional Medical Centre and the Muscular Dystrophy Association prior to data collection. Youths with neuromuscular disease and their parents were recruited through mailings from the rehabilitation medicine, neurodevelopmental, and spasticity clinics at CHRMC, a summer camp for youths with neuromuscular disease, in addition to public postings and word of mouth. Inclusion criteria for youths included primary diagnosis of neuromuscular disease, chronological age between 8 and 20 years, capable of expressive communication using augmentative communication devices as needed, use of English as the primary language, and no more than mild cognitive impairment as measured on a modified Mini-Mental Status Evaluation [4]. Demographic/descriptive data were collected from parent reports and included sex, age, ethnicity, type of NMD, use of mobility devices and orthotics/splints, use of augmentative or alternative communication devices, and income. Youths who reported recurrent bothersome pain of at least 3 months' duration were then queried about pain characteristics and locations. Pain lasting months or longer is considered chronic pain. Each participant was asked specific questions about pain locations throughout the body. Pain intensity was rated specific to each pain location on an 11-point numerical rating scale from 0 to 10 in which 0 = no pain and 10 = pain as bad as could be. Pain frequency, pain duration, and exacerbating and relieving pain factors were participant-identified. The numerical rating scale has been shown to be reliable and valid for youths as young as 5 years of age. Pain interference was assessed

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through use of a modified Brief Pain Inventory [5]. The BPI is a valid and reliable instrument designed to measure pain interference. Degree of interference with daily activities and participation was measured for the primary pain location. The amount of pain interference in the past week was rated using an 11-point NRS where 0 = does not interfere and 10 = interferes completely. Since many persons with physical disabilities may be non-ambulatory, interference with ability to get around replaced the original question of interference with ability to walk. One question was slightly modified for content to make it more age appropriate. To obtain more information on activities and participation, the investigators added items for interference with self-care, social activities, and recreational activities, communication with others, and learning new information or skills. A parent described the child's level of gross motor function using descriptive categories based on a modified Gross Motor Function Classification System. The original GMFCS is a reliable and valid standardized rating system for children with CP to provide an objective classification of their gross motor function. The modification was the addition of the category walks without restrictions and has no limitations in gross motor skills [6]. Youth responded to the Functional Disability Inventory to provide information on disruption of typical physical and social activities, including schoolwork, due to illness, pain, or disability. The FDI is comprised of 15 behaviours related to functioning in child-relevant settings [7]. For example, In the last few days, would you have had any physical trouble or difficulty doing these activities Participants were provided with a visual scale to rate their responses on a 1-to-5 scale where 1 = no trouble and 5 = impossible. The FDI has acceptable psychometric properties. Youths reported on the average duration of pain over the past 4 weeks in the body location they identified as most painful. Youths were also asked to report on the frequency of pain at this or these pain locations in the past 4 weeks, using a scale of 1 to 4 where 1 = always, 2 = daily, 3 = weekly, and 4 = monthly. The parent was asked to identify treatments used for his or her child's pain, using a checklist [8]. The list included physical therapy, transcutaneous electrical nerve stimulation, therapeutic massage, occupational therapy, counselling or psychotherapy, and medications. To eliminate potential influence on responding, parents and their children were queried separately about the youths' experience of chronic pain. For the purposes of this study, the frequency of chronic pain reported by the youths themselves was used for data analysis, rather than the frequency of pain reported by the parents, as this was considered to be a more reliable indicator of actual pain experience. Fifty-three parent-and-child dyads were approached. A total of completed parent-and-child structured questionnaires met inclusion criteria. Of the entire potential participant dyads approached about the study, youths were classified as negligible, and did not pass the modified MMSE and 3 youths were classified by their parents as ineligible. One youth declined to participate. The mean duration of the interview of the youths with pain was 32 minutes [9]. None of the participants used augmentative or alternative communication devices. Of the youths who reported chronic pain, most experienced pain in multiple body locations. Pain in the legs was most commonly reported. Pain interfered with all 12 items on the modified BPI. The range of

interference was mild to severe. There was a wide range of factors that exacerbated pain. They included feeling down, cold weather or being cold, eating, lifting, prolonged sitting or lying, running, standing, and touch. Lesser common strategies that were identified to help relieve pain included changing body position/posture, swimming, and sitting, warmth, changing activity, and wearing socks [10]. Our study indicates that pain is a commonly experienced symptom in youths with neuromuscular diseases.

## Conclusion

Parents reported chronic pain in their children with NMD and more than half of the youth self-reported chronic pain. This finding is consistent with previous studies of adults and youths with various disabling conditions, including spinal cord injury, cerebral palsy, amputation, and neurological injuries. Previous studies in adults with NMD show that a significant percentage has substantial problems with pain, severe enough that it negatively affects both functional capacity and QoL.

## Acknowledgement

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## Conflict of Interest

None

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