

**Title:** Experiences of and perspectives on bullying in youth with Myopathies

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**Brief Summary (50 words):**

Interviews were conducted with youth with myopathies and spinal muscular atrophy who have experienced bullying. Participants often experienced stigma-based bullying (overlap of bullying and discrimination); received helpful supports from family and friends; received unhelpful supports from school; and, have suggestions to help others who experience bullying or to stop bullying.

**Abstract (250-300 words):**

Background: Bullying is an intentional behaviour designed to harm victims. Youth with physical disabilities are more likely to be bullied, especially those with mobility restrictions. Discrimination comes from stigma or social devaluation and involves mistreating people living with or perceived to be living with certain characteristics, and it may be intentional or unintentional. Stigma-based bullying is the overlap of bullying and discrimination. Objectives: To explore bullying experiences and perspectives of youth with myopathies and spinal muscular atrophy (SMA). Methods: Youth with myopathies or SMA (10-19 years old) were approached at two neuromuscular clinics to participate in a larger study, and then were invited to complete a semi-structured interview over Zoom. An example interview question was: "Who is responsible for helping young people with bullying?" Data was analyzed phenomenologically. Two independent researchers conducted inductive coding. Field notes, reflexivity and memoing ensured validity of coding. Results: To date, 14 individuals completed interviews (8 males, 4 females; 11-19 years old) with diagnoses of Duchenne muscular dystrophy (n=7), congenital myopathy (n=1), congenital muscular dystrophy (n=1), myotonic dystrophy (n=3), congenital myasthenic syndrome (n=1) and SMA (n=1). Participants most often experienced bullying in primary school. Preliminarily themes include: 1) participants experience stigma-based bullying; 2) participants receive helpful support through non-school-based initiatives; 3) participants experience unhelpful supports, often from school and teachers; and, 4) participants and their parents have suggestions on how to help. Conclusions: Youth with myopathies and SMA experience unique circumstance when encountering bullying, often at younger ages when their differences begin to show. Earlier screening for bullying is recommended. Additionally, families of children with myopathies and SMA have strategies to minimize bullying and these should be shared.