

Youth with myopathies and SMA experience unique circumstances when encountering bullying.

Experiences of and perspectives on bullying in youth with Myopathies and Spinal Muscular Atrophy

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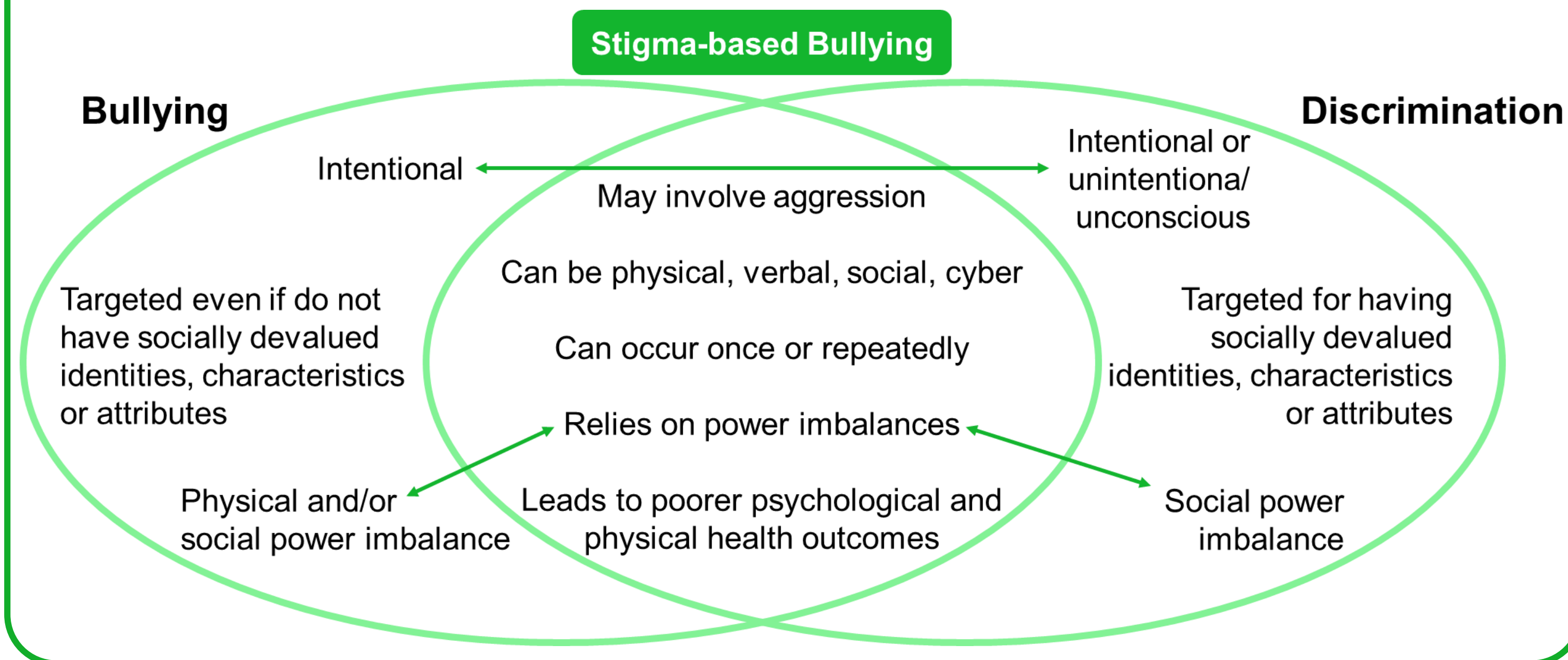
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Bullying

- Bullying = unwanted aggressive behaviour that involves an actual or perceived **power imbalance**, is **repeated or likely to be repeated**, and may **cause harm or distress** to the victim.¹
- Types of bullying: **Physical** (hitting), **Verbal** (name calling), **Social** (exclusion), and **Cyber** (online).²

Discrimination & stigma-based bullying

- Discrimination manifests from **stigma or social devaluation**, and involves mistreating people **living with or perceived to live with** certain identities, characteristics, or attributes.³
- Stigma-based bullying is the overlap of bullying and discrimination.^{4,5}



OBJECTIVE: Explore the experiences of and perspectives on bullying in youth with muscular dystrophy, congenital myopathies and SMA.

Methods

Recruitment & Selection

Youth at Holland Bloorview or CHEO with myopathies or SMA. Participants completed a survey and then were invited for an interview.

Data Collection

Semi-structured interview with participant and/or parent/guardian.

Data Analysis

Analyzed using a phenomenological lens. Transcripts were inductively coded by two independent investigators.

Participants

Gender: 10 male, 4 female

Age: 10–19 years

Diagnoses: Duchenne MD = 7, Congenital Myopathy = 1,

Congenital MD = 1, Myotonic Dystrophy = 3, Congenital Myasthenic Syndrome = 1, SMA = 1 (MD – muscular dystrophy)

Preliminary Themes

Participants experience stigma-based bullying

1. Peers do not understand their disability
2. Peers target participants because of their disability

Helpful supports are initiated by participant & their families

1. Classroom presentations about their disability
2. Peer support
3. Parental support

Participants often experience unhelpful supports at school.

1. Schools' passive prevention strategies
2. Teachers often dismiss bullying victims

Suggested interventions

1. Classroom presentations about disability by family or organizations
2. Buddy programs
3. Build peers' empathy



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