

# Bullying experiences of youth with Myopathies or Spinal Muscular Atrophy and their well-being: A survey study

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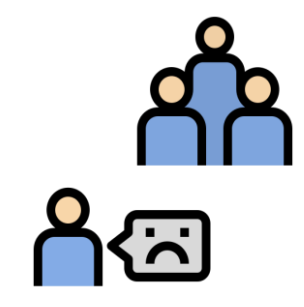
- **1 in 3** Canadian youth have been bullied in their life.<sup>1</sup>
- Bullying = **unwanted** aggressive behaviour involving a **power imbalance, repeated or likely to repeated**, and may **cause harm or distress** to the victim.<sup>2</sup>
- Types of bullying:<sup>3</sup>



**Physical**  
(kicking)



**Verbal**  
(name calling)



**Social**  
(exclusion)



**Cyber**  
(online)

**Objective:** What is the prevalence of bullying in youth with muscular dystrophy, congenital myopathies or spinal muscular atrophy (SMA), and how does it impact their quality of life (QoL) and well-being?

## Participant Inclusion Criteria

- 1) Youth with muscular dystrophy, congenital myopathies or SMA
- 2) 10-19 years old
- 3) Able to read in English or French

**Survey** – all measures at one time point on RedCap

Demographics	Bullying frequency	Bullying thoughts
Quality of Life (KIDSCREEN-10)		Well-being (EPOCH)

## Data Analysis

- Descriptive statistics: demographic and bullying data.
- Spearman Rank Order Correlations: bullying prevalence and quality of life/well-being.

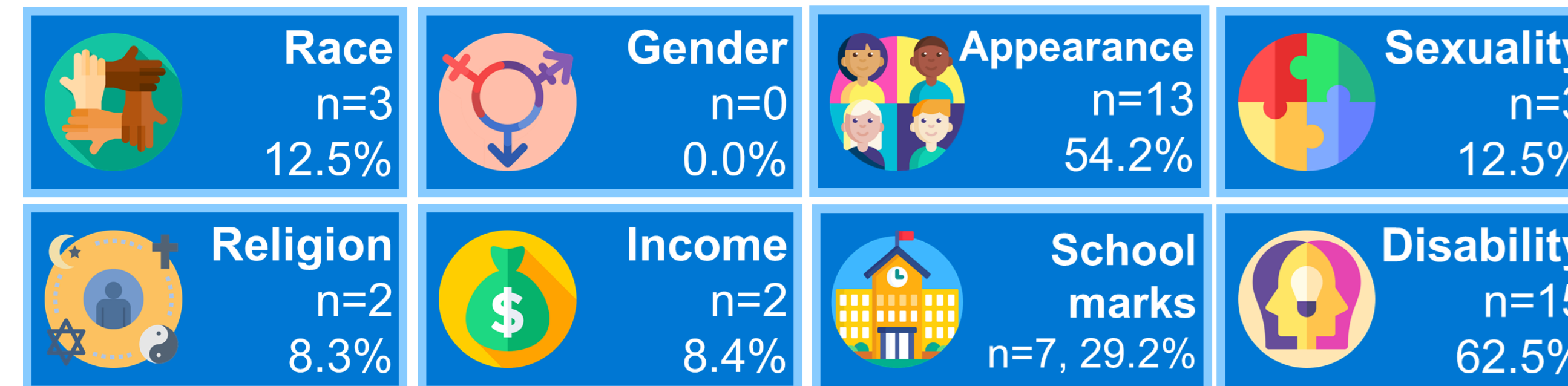
**Participants (N=29)** • **Age:** 13.9 ± 2.9 years; **Gender:** 22 male, 7 female

- **Diagnoses:** Duchenne MD (n=16), Becker's MD (n=2), Central Core Myopathy (n=1), Congenital Myasthenic Syndrome (n=1), Congenital Myopathy (n=1), Congenital MD (n=2), Mitochondrial Myopathy (n=1), Myotonic Dystrophy (n=4), Spinal Muscular Atrophy (n=1)

## Bullying Frequencies

At some point in my life...	N	Never		Once/twice		3 or 4 times		Every day	
		n	%	N	%	n	%	n	%
I have been bullied	29	5	17.2	11	37.9	10	34.5	3	10.3
I have been bullied physically	24	17	70.8	3	12.5	4	16.7	0	0.0
I have been bullied verbally	24	3	12.5	13	54.2	4	16.7	4	16.7
I have been bullied socially	24	4	16.7	11	45.8	7	29.2	2	8.3

**Reasons for Being Bullied** – frequency (n, %) of participants



## Correlations

$\rho$ (p)	QoL	E	P	O	C	H
<b>Bullied in my life</b>	-0.36 (0.05)	0.07 (0.70)	-0.10 (0.62)	0.22 (0.25)	0.22 (p.26)	0.08 (0.68)
<b>Physically bullied in my life</b>	-0.01 (0.96)	0.24 (0.25)	-0.24 (0.26)	0.03 (0.89)	-0.32 (0.13)	0.25 (0.24)
<b>Verbally bullied in my life</b>	-0.17 (0.42)	-0.10 (0.66)	<b>-0.48 (0.02)</b>	0.18 (0.40)	-0.24 (0.25)	0.05 (0.83)
<b>Socially bullied in my life</b>	-0.30 (0.15)	-0.39 (0.47)	-0.01 (0.96)	0.35 (0.10)	0.09 (0.67)	-0.12 (0.57)

\*E=engagement, P=perseverance, O=optimism, C=connectedness, H=happiness; Statistical significance, p<0.05

Youth participants with myopathies or SMA showed stable quality of life and well-being even if they experienced bullying. Is it because they have higher resilience and better coping skills?

## References

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- Significantly **lower perseverance** was associated with **higher** rates of **verbal bullying**.
  - We hypothesize a mediating factor contributes to the lack of changes in QoL and well-being.
    - A systematic review reported lower QoL and well-being in school-aged youth who were bullied.<sup>4</sup>
    - However, youth with chronic illnesses often exhibit no psychosocial risk factors and are **resilient**.<sup>5</sup>
- Does this explain participants' stable QoL and well-being even when they experience bullying?



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