

Background

- Children and youth ('youth') with spina bifida (SB) are more at risk for developing higher weights
- Youth with SB may face neurological differences, cognitive impairments, metabolic irregularities, mobility challenges, or structural barriers to accessing care and services that can lead to higher weights
- Little is known about how these youth conceptualize bodyweight and health
- Learning how youth and families understand weight is important - it may impact their lifestyle behaviors and engagement in weight-management services

Research Objectives:

- 1) Explore how youth with SB and their parents define bodyweight, health and weight management
- 2) Identify the services and type of support youth with SB and their families want to help them with weight management



Results

Three themes were developed using inductive thematic analysis.

1. Larger bodies are unhealthy bodies

- Defining health based on bodyweight and size
- Seeing a bigger body as unhealthy
- Idealizing weight loss (especially by the girls and their mothers)
- Considering only a moving body as a healthy body

2. Dietary decisions govern bodyweight

- Focusing on food intake was main approach to weight management for many families
- Dichotomizing food into good vs. bad foods
- Responsibility for nutrition and weight management was placed on mothers

3. Supports need to be multifaceted

- Having safe and trusting relationships with HCPs were critical to having positive weight-related conversations
- Engaging youth directly in their own care was seen as a priority
- Making activities fun and providing practical tips were desired by both youth and parents

Methods

- Qualitative research using Interpretative Description
- Semi-structured interviews with youth with SB and their parents; conducted between 2018-2020
- All youth had received care from a children's hospital in Ontario
- Youth were eligible if they were: 10 to 18 years old; diagnosis of spina bifida; received care from a children's hospital/centre in Ontario; could communicate short phrases in English; and had prior discussion about weight with a health care provider
- Interviews conducted in-person or by Zoom
- Thematic analysis where team consensus guided coding of data into themes

Participants (n=10)

- 5 youth participated between the ages of 12-16 years
 - 3 youth identified as girls and 2 identified as boys
- 5 mothers participated and were from Latin, Asian and European cultural backgrounds.

I was told by one of my like family members, they said that I look like I've lost a little bit of weight, that made me like feel good (Teenage Girl)

She avoids a lot of things [...] like a pastry [...] she says, 'No I won't eat it because it's affecting my weight' (Mother)

I learned to trust them more [...] if I have a concern, they are not just going to think I'm weird or obnoxious, they are going to answer the questions (Mother)

Key Take-Aways

- Weight-management approaches should reflect families' needs and include youth
- Conversations should happen more often given that youth with SB are more at risk for higher weights
- More education is needed so that health is not seen as solely linked to bodyweight
- These findings may be applicable to other youth with mobility impairments