Young people with SBH may be at a higher risk of disordered eating, eating disorders and negative body image.

Exploring the extent and nature of disordered eating in adolescents and young adults with spina bifida and hydrocephalus: An interim analysis

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Background
• Young people with spina bifida and/or hydrocephalus (SBH) are thought to be at a higher risk for under- and over-eating.
• However, we lack information on the eating patterns and behaviours of young people with SBH, and how they perceive their body image.
• It is also unknown whether eating patterns, dietary manipulation, and disordered eating behaviours are being identified and addressed in clinic settings.

Purpose
• This study explores the nature, extent, type, and frequency of disordered eating behaviours amongst young people with SBH.
• It also aims to understand their perceptions surrounding their body image.

Methods
• Self-report, cross-sectional online survey of young people (aged 12-26) with SBH:
  • Includes validated measures to assess eating behaviours, disordered eating and body esteem;
  • Questions also created by our team addressing eating patterns related specifically to SBH.

Results (n=16)
• Participants (mean age = 21) identified as non-binary (6%), female (76%), and male (18%).
• Compared with a sample of young people without disabilities, participants showed greater eating, shape, and weight concerns.
• Compared with a sample of children without disabilities attending a paediatric weight loss program, the SBH sample were more likely to engage in emotional eating.
• Healthcare provider discussions could influence behaviour.

• Having SBH affected the way some participants viewed their body.
  • “It makes me extremely self-conscious”
  • “The beauty standard is able bodied”
  • “…I felt that I wasn’t as attractive due to my spina bifida. I have a great dislike for the body parts that have been affected by spina bifida”
  • “I feel really insecure about my body”

Conclusion
• This interim analysis suggests that disordered eating, eating disorders & body image may be important issues in young people with SBH.
• These could potentially be safely addressed in clinical settings but additional training for healthcare providers will likely be needed.
• Recruitment for the study is ongoing.