An environmental scan of weight assessment and management practices in paediatric spina bifida clinics across Canada

Amy McPherson, PhD, CPsychol, AFBPsS
Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Dalla Lana School of Public Health, University of Toronto, Toronto, ON.*

Jennifer Leo, PhD (c)
Abilities Centre, Whitby, ON. Jennifer Leo conducted this work whilst at Bloorview Research Institute.

Paige Church, MD.
Julia Lyons, RN.
Lorry Chen, RD.
Holland Bloorview Kids Rehabilitation Hospital, Toronto, ON.

Judy Swift, PhD.
University of Nottingham, UK

* Please address correspondence to:
Amy McPherson, PhD.
Holland Bloorview Kids Rehabilitation Hospital
150 Kilgour Road
Toronto. M4G 1R8
Tel: (001) 416-425-6220 ext. 6378
Fax: (001) 416-425-1634
Email: amcpherson@hollandbloorview.ca

Citation for published version:
Abstract

Childhood obesity is a global health concern, but children with spina bifida in particular have unique interacting risk factors for increased weight. **Purpose:** To identify and explore current clinical practices around weight assessment and management in paediatric spina bifida clinics. **Methods:** An online, self-report survey of healthcare professionals (HCPs) was conducted in all paediatric spina bifida clinics across Canada (15 clinics). Summary and descriptive statistics were calculated and descriptive thematic analysis was performed on free text responses. **Results:** 52 responses across all 15 clinics indicated that weight and height were assessed and recorded most of the time using a wide variety of methods, although some HCPs questioned their suitability for children with spina bifida. Weight and height information was not routinely communicated to patients and their families and HCPs identified considerable barriers to discussing weight-related information in consultations. **Conclusion:** Despite weight and height reportedly being measured regularly, HCPs expressed concern over the lack of appropriate assessment and classification tools. Communication across multi-disciplinary team members is required to ensure that children with weight-related issues do not inadvertently get overlooked. Specific skill training around weight-related issues and optimizing consultation time should be explored further for HCPs working with this population.

**Keywords:** rehabilitation, children, disability, spina bifida, obesity
An environmental scan of weight assessment and management practices in paediatric spina bifida clinics across Canada

INTRODUCTION

Spina bifida is now considered a non-progressive, life-long condition, although the longer lifespans made possible with modern medical advances (1, 2) may be severely compromised by overweight and obesity (3, 4). The prevalence of obesity in young people with spina bifida has been calculated as approximately twice that of their typically developing peers, with numbers cited up to 50% in children, and 64% in young people up to 24 years (5, 6). They have also been shown to have increased levels of body fat, decreased lean body mass and decreased physical fitness levels (6, 7), all of which have significant implications for morbidity and mortality. For example, mobility can be further impaired; catheterization, toileting and other self-care activities become more difficult; there is added pressure on skin already vulnerable to break-down; and social isolation can be intensified. This can lead to decreased quality of life (5, 8). This often results in a cycle of disadvantage that has serious ramifications later in life, both for health and participation in society (9, 10). Tackling weight management in childhood is therefore vital to preserve quality of life, and may prevent additional morbidity over the course of their lifetime. However, although intervention with dietary and physical activity advice is recommended, it is frequently not implemented (5).

The physical consequences for any overweight or obese child are well documented (11, 12), potentially resulting in life-threatening conditions such as heart disease, stroke, respiratory disease and infections (8, 13). For those with existing disabilities, severe secondary conditions and symptoms such as extreme muscle loss, pain, pressure sores, mobility limitations and depression (14, 15) can further hinder independence, limit activities (16, 17) and further increase
isolation and exclusion (18).

Children with spina bifida in particular may have a unique set of interacting risk factors for obesity. Brain malformations (e.g. Chiari II) can cause problems with swallowing and gagging, limiting food intake to specific tastes or textures and thereby affecting food preferences (5). Mobility impairments can result in sedentary lifestyles and reduced physical fitness (19, 20). Metabolic irregularities and lower resting energy expenditure can make it challenging to achieve or maintain a healthy bodyweight (7, 21), especially in children with a high level of paralysis (6, 22). Furthermore, issues such as bowel and bladder function may influence children’s dietary behaviours more than a desire to optimize weight management (23), which must be taken into consideration when discussing weight-related issues.

**Current clinical practice**

The Canadian Pediatric Society (24), American Academy of Pediatrics (25), and the Royal College of Paediatrics and Child Health in the UK (26) all advocate that children aged two years and older should have their growth monitored. Current guidelines by the Centers for Disease Control and Prevention (CDC) use Body Mass Index (BMI; calculated as kilograms per metre squared) as a proxy for body fat and consider a child 2-18 years between the 85-95th centile as overweight and above the 95th centile as obese (27). Visits to HCPs- whether or not for a weight-related matter- offer an ideal opportunity for such monitoring for all children. However, the assessment and recording of typically developing children’s weight and BMI by healthcare professionals (HCPs) varies enormously (28, 29). Currently, little is known about what happens with other paediatric populations, such as those with disabilities.
Considering their potentially increased risk of obesity (5, 6) this issue is of particular significance for children with spina bifida. However, in a recent review of 180 medical records of 2-18 year olds with a diagnosis of spina bifida conducted at a major urban rehabilitation hospital, only half (n=96; 53.3%) had a weight recorded in their medical records at least once in the preceding 36 months, and no documentation of BMI was found in any of the records. Although overweight/obesity was mentioned within some of the consultation notes, this rarely corresponded with recorded weight information (23).

A significant challenge in weight assessment and management is that, in terms of body composition, young people with spina bifida frequently have a higher percentage of body fat and lower lean body mass than the typically developing population (21, 30), as well as being shorter than their peers (7, 31). Even measuring height can be problematic among children with contractures (21). Arm-span - where arms are extended against a wall for measurement- has been used as an alternative to height for those who cannot stand or have neuro-muscular weakness (6, 32), although this can be challenging for some children with disabilities. Ulna length has also been used as a proxy for height- again with prediction equations developed (32) but its clinical use in this population is not known.

Furthermore, although BMI assessment is simple, inexpensive, and noninvasive (33), it is only a proxy for body fat and does not assess body composition itself. Therefore, BMI can underestimate the amount of fat in people with less lean muscle mass, including those with spina bifida. Consequently, the use of BMI and classifying weight according to the cut-offs used with typically developing children as the primary indicator of overweight and obesity has been criticized (7, 22), but there is currently no gold standard alternative for assessing and classifying the weight of children with spina bifida. Waist circumference and skinfold thickness have been
shown to correlate well with fat mass as measured by dual-energy X-ray absorptiometry (34, 35) and have been specifically recommended for assessing body fat of children with spina bifida for research purposes (30). However, although waist circumference is a relatively quick and simple procedure, accurate landmarking of the waist is required and it is unclear how frequently this method is used in a clinical setting. Skinfold thickness- where calipers are used on a number of body sites (conventionally 5 or 7 different sites) to ‘pinch’ the skin- is also a relatively non-invasive & inexpensive way of estimating percent body fat (36), although can be time-consuming and has high intra-measurement error if the assessor is not skilled (33 ). Other methods of assessing children’s weight and body composition (e.g. dual-energy X-ray absorptiometry) require costly, specialized equipment rarely available in ambulatory clinics. Therefore, we currently lack understanding of how spina bifida clinics assess children’s weight and body fat, and classify it in order to identify potential weight problems.

It is also important to consider that weight monitoring alone is insufficient without communicating it to the child and their family (24). Healthcare professionals’ interactions with parents and children represent a critical tool in healthy weight management (37, 38), yet many report having difficulties discussing weight-related matters with typically developing children and their families (39, 40). In a spina bifida context, multi-disciplinary HCPs (e.g. paediatricians, physiotherapists, occupational therapists and nurses), as well as more specialist roles (e.g. psychologists and dieticians), may all provide care for children and families. However, we do not know which HCPs discuss weight management within a spina bifida context or how they do so. It is therefore crucial to determine where the responsibility for weight management is perceived to lay by the different members of spina bifida healthcare teams, as well as identify any barriers that may preclude them from communicating about weight-related issues. This is not restricted to
children who are already overweight or obese, as obesity prevention is an international health promotion strategy (41, 42).

**Research gap**

Children with spina bifida appear to have a unique set of interacting risk factors for obesity. Little is known about how spina bifida clinics assess, classify and monitor weight in this population, and we do not understand how HCPs communicate about weight-related issues or the barriers they face. Therefore, this environmental scan had two objectives: 1) To identify the anthropometric measures clinics providing care for children with spina bifida use, and their perceived utility; and 2) To describe how professionals report discussing weight-related issues with their patients attending paediatric spina bifida clinics. Our specific research questions were as follows:

1) What anthropometric assessment methods are used in out-patient spina bifida clinics?
2) When is weight and height assessed and by whom?
3) What is the extent and nature of discussions about weight management and weight-related lifestyle behaviours (e.g. physical activity and diet) with patients and their families?
4) What barriers exist to discussing weight-related issues with children and their parents, and providing appropriate advice?

**METHOD**

**Sample**

A Canada-wide scan in 2009 identified a total of 13 out-patient clinics offering specialist
paediatric spina bifida care (43). Multi-disciplinary teams of HCPs are the preferred model of care for children with spina bifida (31), which, depending upon their size, may include a combination of any of the following: nurse, paediatrician, physiotherapist, urologist, orthopaedic surgeon, psychiatrist (a specialist in physical medicine and rehabilitation), occupational therapist, social worker, and dietician. Any healthcare professional who had contact with children with spina bifida within one of the 13 identified clinics across Canada was eligible to participate in this study. Clinics in one Province (Quebec; n=2) were not included in the original report, so they were also invited to participate, resulting in a total of 15 clinics invited to participate in the study.

**Measures**

An online, cross-sectional, self-report survey of the weight assessment and management practices of clinics providing care to children with spina bifida across Canada was developed by the multi-disciplinary research team. This contained both quantitative and qualitative sections, and was uploaded onto a Canadian-based survey website (www.fluidsurveys.com). The survey requested information on anthropometric assessments used by clinics. Barriers to weight management and weight-related discussions experienced by individual professionals were also identified and explored in more detail, to capture the variation in experiences. Items were derived from the limited literature on weight management in children with disabilities and spina bifida, and augmented with literature from typically developing children, clinical expertise and findings from the group’s earlier medical record review (23). Some of the questions invited open answers and explored the challenges and best practices in weight management among children with spina bifida in more detail. The questionnaire was pilot tested with a healthcare professional who
formerly worked in the local spina bifida clinic and was independent to the research team, to test the readability and clarity of the items, as well as the time for completion and its functionality as a web-based survey. Following the pilot, no questions were removed and only minor rewording of two questions was required. The final version of the survey included 43 questions using a variety of formats such as multiple choice, Likert-type rating scale, yes/no, and free text response, and took approximately 15-20 minutes to complete. A copy is available from the first author.

**Procedure**

Following ethical approval from the institutional review board at the rehabilitation hospital where the first author was located, an introductory letter was sent to a key contact identified at each of the spina bifida clinics in the aforementioned report. The following week they received an email containing an information letter with the online survey link, with a request to distribute it to all healthcare providers in their team. Completion of the anonymous survey implied consent. A follow-up telephone call was made to the key contact at each clinic within a week of providing the survey information to answer any questions.

The Dillman Survey Design Method (44) was used to maximize our response rate: approximately 2 weeks after the original mail-out, an email reminder was sent out via the clinic contacts, thanking those who had already responded and reminding non-responders of the website link. A final reminder was sent after another 2 weeks. Upon completion of the survey, respondents had the opportunity to enter a draw to win one of two $100 gift cards. Their contact details were recorded via a separate webpage so that they were not linked to their survey responses at any time. Paper copies of the survey were provided to three clinics at their request.
Data analysis

Numerical data were analysed using SPSS Version 19.0. Summary and descriptive statistics (frequencies, means, standard deviations, and ranges) were calculated on the sample. Key issues were identified from the free-text sections to enhance the quantitative responses where appropriate. Data from participants with incomplete surveys were included where available, with missing values on individual variables excluded from analysis (pairwise deletion), considered appropriate for the purpose of calculating descriptive statistics (45). The number of responses used to generate the results below is indicated throughout the results section to indicate where there were missing data.

RESULTS

Response rate

There were 52 responses with surveys completed by at least one member of each of the 15 spina bifida clinics (our primary interest), indicating a clinic participation rate of 100%. We estimated that approximately 100 multi-disciplinary HCPs could be involved in delivering care at the 15 spina bifida clinics (approximately 6 per clinic). Therefore the estimated response rate was approximately 52%. To promote candour, surveys were completed anonymously. Therefore, it was not possible to identify how many responses were received from each individual clinic.

Respondents were distributed across the country, with 26.9% located in Western Canada, 55.7% in Central/Northern Canada, and 17.3% in Atlantic Canada. There were a total of 32 complete responses, and 20 partial responses, which was thought to be largely due to some participants encountering technical difficulties.
Description of participants

Respondents had an average age of 48.9 years (range: 24 - 78 years old) and represented the following healthcare professions: registered nurses (32.7%), physiotherapists (21.2%), physicians (17.3%), dietitians (7.7%), occupational therapists (5.8%), psychologists (5.8%), social workers (5.8%), speech language pathologists (1.9%), and therapeutic recreation specialists (1.9%). Participants had held their professional designations from 1 to 47 years, with an average 23.7 years of experience in their field.

Description of clinics

Participants in this study represented clinics who provided services to children and youth with spina bifida and spinal cord injury (36.7%), spina bifida only (32.7%), and other conditions (including any physical disability, neuromuscular, other congenital conditions) (28.6%). The majority (60.5%) of clinics provided services to at least 100 patients with spina bifida annually. Between 4 and 14 children and youth with spina bifida received care at each clinic session. Participants described these clinics as taking place two days per month (54.7%), once per month (21.4%), once per week (14.2%), and quarterly (4.8%). The remaining 2 responses were unclear (i.e. “school based program” and “only if consulted, so I don’t know”).

Current Practice

Measuring height and weight

Overall, the results suggested that height and weight were measured regularly (see Table 1). From 46 responses (reflecting 6 missing responses), a variety of height assessment approaches were reported: 41 (89.1%) indicated height was measured while standing, 34 (73.9%)
measured height in the supine position, 17 (36.9%) used arm-span, 2 (4.3%) used an arm-board, and 1 (2.2%) measured ulna length to determine height (categories not mutually exclusive).

A range of approaches were also employed to measure weight: the majority reported measuring weight while patients were standing (n=39, 84.8%), sitting (n=32, 69.6%), using a wheel-on scale (n=33, 71.7%), and while patients were supported by a hoist or lift (n=10, 21.7%) (categories not mutually exclusive).

Nurses were reported to be primarily responsible for measuring height and weight (n=33, 75%), followed by other non-designated staff that included a health care aide, unit aide (foreign trained nurse), and licensed practical nurse (n=7, 15.9%), followed by an administrative support person (n=2, 4.5%) and physician (n=2, 4.5%).

The respondents also reported conducting other body composition assessments, with two indicating that waist circumference was used and two identifying skinfold thickness measurements.

Over half of the 43 respondents indicated that guidelines existed in their clinic regarding the frequency of assessing height (n=24, 55.8% reported yes) and almost two thirds of assessing weight (n=27, 62.8% reported yes). The most common guideline was described as every clinic visit (n=13, 30.2%), followed by annually (n=4, 9.3%), and every six months (n=3, 7.0%).

**Perceived value of monitoring height and weight**

Qualitative responses identified the importance respondents attributed to monitoring height and weight among children and youth with spina bifida. For example, one respondent explained, “They need to be followed by the dietician at some point. It is very important to watch their weight gain as their back and limbs suffer due to excess weight” (Nurse, 34 years in
practice). Another respondent revealed, “Adolescents usually have growth spurts, so you need to monitor the weight and height, weight especially for wheelchair bound patient.” (Nurse, 37 years in practice). BMI was identified as an appropriate tool to monitor height and weight by one dietician, 5 years in practice: “I think it is essential to calculate and plot BMI or weight for length for all spina bifida patients, however this is rarely done.”

Monitoring BMI (n= 18) and referring to the Centers for Disease Control & Prevention (CDC) growth chart (n=16), or World Health Organization (WHO) growth charts (n=14) were all reportedly employed. However 22 out of 37 respondents (59.5%) reported that they considered these methods inappropriate for use with a spina bifida population, because they often did not fall within the norm standards of available tools (e.g. WHO or CDC growth charts), due to their varying body composition. No adaptations of these established methods of evaluating weight were reported (e.g. using different cut-off points), although lack of appropriate assessment tools was identified as a significant gap in clinical practice;

“I think we should be using some type of measure to evaluate this population. Most of the time, we make a subjective judgment about the child’s weight... If I was going to use a measure, and for the few children I have, we used BMI. But we have not explored best practice guidelines on this topic, so I don't know if there are better tools.”

(Physiotherapist, 15 years in practice)

Discussing weight

Out of 41 responses, 27 (65.8%) reported that discussions around weight occurred ‘always’ or ‘most of the time’, although two (4.8%) reported that they ‘rarely’ or ‘never’ took place (see Table 1). Nurses (n=31, 75.6%) were reported by the majority as being responsible for
discussing weight-related issues with children and families, followed by physicians (n=28, 68.3%), dietitians (n=22, 53.7%), physiotherapists (n=15, 36.6%), occupational therapists (n=6, 14.6%), social workers (n=3, 7.3%), and recreation therapists (n=3, 7.3%) (categories not mutually exclusive). The triggers for discussing weight endorsed by respondents (n=41) included: issue was identified by parent and/or child (n=35, 85.4%), increased weight velocity on a growth chart (n=33, 80.5%), BMI (n=23, 56.1%), family history (n=17, 41.5%), relevance for pain management (n=14, 34.1%), and other (n=7, 17.1%), which included decreased mobility, self-esteem issues, and preparing for surgery. To support these discussions, participants (n=34) used resources such as Canada Food Guide, Canadian Physical Activity Guidelines, or other nutrition documents (e.g. a handout on fibre) ‘always’ or ‘most of the time’ (47.1%), ‘sometimes’ (47.1%), and ‘rarely’ or ‘never’ (5.8%).

Participants were asked to select the most appropriate professional to both identify and coordinate weight related issues among children and youth with spina bifida. Of the 34 respondents, physicians (35.3%) were chosen as the most appropriate professional to identify weight related issues, followed closely by dietitians (29.4%), and nurses (20.6%). In terms of coordinating weight-related care, the majority of participants identified nurses (44.1%) as primarily responsible, followed by dietitians (32.4%) and physicians (11.8%).

The majority of the 34 respondents reported that patients were referred to specialized weight management programs ‘sometimes’ (44.1%) or ‘never’ (11.8%) (see Table 1). When asked to identify the referral criteria for such services, BMI (n=15, 44.1%), obesity-related comorbidity (n=17, 50.0%), co-existing chronic condition (n=11, 32.3%), and age (n=4, 11.8%) were identified (not mutually exclusive). Eight participants (23.5%) reported that they did not know the referral criteria for their clinic.
**Barriers to regular assessment/providing care**

Insufficient time (n=19, 41.3%) was reported as the most common reason that height and weight were not being assessed, followed by lack of equipment (n=7, 15.2%), and lack of expertise (n=3, 6.5%).

Of 33 respondents, the majority (n= 23, 69.7%) revealed that overweight or obesity impacted their ability to offer a particular intervention or treatment plan for a child or youth with spina bifida. The impact of the excess weight was qualitatively described as interfering with the performance of activities of daily living, increasing the risk to HCPs (e.g. transfers become more difficult), and obstructing the completion of testing or surgical procedures. According to one respondent, excess weight “raises safety issues for care givers and therapists during transfers and treatment. Child might be considered high risk candidate for surgery.” (Physiotherapist, 18 years in practice)

Participants also revealed a lack of confidence discussing weight management issues with patients. Only 25% (n=8) described themselves as ‘confident’ or ‘very confident’ and 43.7% (n=14) reported being ‘not confident’ or ‘not at all confident’ when asked to rate their level of confidence (on a 1-5 scale) in addressing the topic of weight management (total n=32). Strategies that respondents’ reported as potentially addressing this lack of confidence included: having better management options available (n=19, 59.4%), receiving obesity-specific training (n=18, 56.3%), greater patient engagement with the topic (n=17, 53.1%), more consultation time (n=17, 53.1%), having the discussion initiated by the family (n=15, 46.9%), and better measurement tools (n=9, 28.1%).
DISCUSSION

Overall, weight and height were reportedly being assessed and recorded most of the time in out-patient clinics providing care to children with spina bifida across Canada using a wide variety of methods. Skinfold thickness and waist circumference were infrequently employed. Height was measured primarily with the child standing, which has implications for accuracy given the lower limb contractures that many children with spina bifida have.(21)

Responses suggest that insufficient time, lack of equipment and expertise are possible reasons that the clinics may not be implementing these methods. Respondents also varied in the extent to which they felt the tools available were appropriate for this specific population, along with a desire for clearer guidance for their own practice. Specifically, HCPs expressed a concern over the lack of spina bifida-specific tools to interpret weight and height data and therefore determine if children or youth are overweight or obese. Certainly, the significant implications of excess weight in this population were highlighted, as nearly 70% of respondents felt that it impacted their ability to offer a particular intervention or treatment plan, such as surgery, tests or transfers. It is possible that the remaining 30% had not previously considered weight as an important factor, given the multiple health complexities already being managed (31). However, they may be more sensitized to the issue since participating in the environmental scan.

Despite weight and height reportedly being regularly measured, this information was not routinely being communicated to patients and their families. One reason may be that respondents differed in their identification of which professional would be best suited to both identify weight issues and also discuss them with children and families. Some of the barriers to weight-related discussions identified (e.g. lack of time and training) are similar to literature relating to typically developing children (e.g. (46). However, additional barriers to incorporating weight-related
information in spina bifida consultations were identified, and gaps in knowledge and availability of specialist obesity services for children with spina bifida were notable.

The data obtained in this environmental scan were congruent with some previous work in this area, particularly the range of professionals perceived to be responsible for weight identification, management and discussion (23, 47). However, there were also some key differences, as the majority of survey respondents reported that weight and height were assessed and recorded always or most of the time in their clinic, whereas literature with typically developing children shows inconsistent clinical practices in this regard (28, 29, 48), and a recent review of spina bifida clinic records revealed that only half of the medical records reviewed had even one weight recorded in the preceding 36 months (23). It should be noted that this medical record review was only conducted in one site, and therefore may not be representative of all clinics. However, the subjective nature of self-report data (as used in this current study) also needs consideration, as self-report has been shown to over-estimate the rates of both individual and centre-wide clinical practices (49), including the assessment of weight and height of children (40).

Current literature suggests that identification of obesity is associated with improved weight management (50), which highlights the need to identify best practices related to assessing, identifying, and managing overweight and obesity in children. However, for children with spina bifida, even when weight is assessed, the options for monitoring and classifying are currently limited; in this survey, only 41% of respondents felt that currently available tools such as growth charts were appropriate. Concerns raised by respondents related to the use of BMI with this population are supported in the literature (7), as differences in body composition in individuals with spina bifida may lead to an under estimation of obesity according to the
traditional BMI cutoff criteria (22). The reliance on BMI and its potential underestimation is therefore concerning because children may unknowingly be at considerable risk of negative health outcomes without receiving appropriate attention. We did not specifically ask whether existing methods for categorizing weight were being modified by clinics for use with spina bifida populations (e.g. using a higher or lower cut-off point for BMI) so it is possible that individual clinics were using such adaptations. However, none were reported. Over a quarter of respondents reported that this lack of appropriate measurement tools hindered their ability to address weight management in children with spina bifida. When used with typically developing children, growth charts have been previously reported to be a powerful tool to facilitate consultations with parents around their child’s weight (39). There is therefore a clear need to develop new tools for weight assessment, classification and management for this population given their unique needs.

Guidance on the interpretation of growth data, taking into account typical body composition in children with spina bifida, is key to this and is currently lacking.

Lack of confidence was identified by a considerable proportion of respondents in this survey as a barrier to addressing weight management with clients attending spina bifida clinics. Only 25% of respondents rated themselves as confident or very confident in addressing weight-related issues in consultations, despite nearly 70% of respondents indicating that overweight and obesity negatively impacted their ability to provide care or treatment to children with spina bifida. Healthcare professionals have previously reported difficulties broaching the subject of obesity with typically developing children and/or their parents (39, 40, 51) although our environmental scan suggests that the underpinning reasons may be different in a spina bifida context. A detailed exploration of the difficulties HCPs face when talking about weight in spina bifida clinics would help elucidate these difficulties further. In typically developing children,
nurses report using strategies such as using tactful language, negotiating the parents’ own weight status, and understanding different cultural belief systems (39). Whilst these are also likely to be pertinent when communicating with children with spina bifida and their families, the results of this survey suggest that there are likely to be additional issues to take into account. Interactions between HCPs and families can greatly influence children and families’ receptivity to weight counseling (37, 52), so it is imperative that discussions about weight-related issues are sensitive, patient-centred (53), and tailored to the child’s specific needs. Increased professional knowledge specific to obesity, was identified by survey respondents as one strategy to improve their confidence and ability to address weight issues, along with more consultation time and greater family engagement with the topic. Although additional consultation time is unlikely to become available, appropriate training could potentially assist HCPs to optimize the available time by addressing priority issues for all stakeholders.

Different professionals were identified as holding primary responsibility for initiating the conversation and monitoring the ongoing progress of weight management. For example, physicians were selected to identify the issue and nurses were reported to be responsible for monitoring. Dietitians were also perceived as having expert knowledge to address this issue, despite not every clinic having this resource. Considering the diversity of professionals within each clinic, effective and ongoing communication within a multi-disciplinary clinical team is essential to coordinate weight management practices. Working within a frame of coordinated care and partnership between HCPs, individuals with spina bifida and their families, it is essential to provide comprehensive care that includes weight management strategies (47).

**Strengths and limitations**
Online surveys provide a relatively low cost method to measure the perceptions of HCPs across a wide geographical area (54). However, it can be difficult to measure absolute response rates (55). In this study the survey link was electronically distributed by each individual clinic and therefore the total number of potential participants was unknown. Nevertheless, each of the 15 clinics invited to participate was represented by at least one respondent (giving a clinic response rate of 100%), providing confidence that our results are representative of clinics across Canada, which is our primary interest.

An estimated response rate of 52% is consistent with other online surveys (56). Completion rate, which examines the ratio of participants who finished the survey after indicating a willingness to do so (i.e. by clicking on the first page) was 57.6%, which is relatively high compared to an online survey of burn care specialists which identified a completion rate of only 12.1% (57).

The majority of respondents in this study were extremely experienced in their field, increasing the likelihood that they had comprehensive knowledge of the clinical practice that this study wished to capture. Newly qualified practitioners also contributed their views, providing a range of different experiences.

As previously noted, self-reported behaviours may over-estimate actual clinical practices (49). However, participants revealed significant gaps in knowledge, confidence and practice, suggesting that they were being reasonably candid. It should also be noted that the survey tool was constructed specifically for this study, so the reliability and validity of the instrument is unknown. However, this is in keeping with standard practice in environmental scans (58, 59).

Multiple reporting from different clinics potentially inflated the prevalence of particular assessment methods if one clinic yielded more responses than others. Unfortunately, it was not
possible to analyze the data from each clinic separately due to confidentiality and privacy reasons. The majority of responses were from nurses, followed by physicians, with few responses from dietitians (7.7% of the sample), suggesting a response bias. We do not know exactly how many clinics have dietitian involvement, although it is not every clinic.

**Clinical implications**

Spina bifida clinics in Canada report having a wide range of guidelines around the frequency and method of anthropometric assessments, although clinical practices in healthcare systems outside Canada may be different within systems using varying reimbursement models (60). Ideally, a clinical or integrated care pathway should be developed to provide organization and goal-defined planning (61), along with clarity on the roles and responsibilities related to weight management for each of the HCPs, and appropriate criteria for referring to specialized obesity services. Such clinical practice guidelines would provide consistency to this aspect of clinical practice. They could also be used to guide resource usage at the clinic level, as well as provide Canada-wide statistics around obesity in children with spina bifida, which are currently absent from the literature. To ensure comparability, it is particularly important that such clinical practices are standardized across clinics- for example, whether a child is clothed or wearing orthoses when weighed. The utility and accuracy of using different measures of height (e.g. standing, arm span or ulnar length) must also be considered, given the challenges of accurately measuring height in this population. The variation in size and make-up of different spina bifida clinics must be taken into account, requiring some flexibility in guidelines.

Despite the clear need for clinic guidelines on weight management, there is currently no robust evidence upon which to base them. It is also premature to recommend one form of
anthropometric assessment over another at this current time, given the lack of evidence. The feasibility and utility of methods such as waist circumference or skin-fold thickness needs to be thoroughly evaluated before being recommended. Professional development opportunities across disciplines will also likely be required to build clinician confidence in addressing weight issues.

**FUTURE RESEARCH**

Clinicians in this study, as well as researchers in the field (7, 22) have identified that BMI and growth charts developed for typically-developing children are inappropriate for use with children with spina bifida. However, very few clinics in our survey employed alternatives. Waist circumference requires minimal resources and is worthy of further exploration in a clinical practice setting.

Barriers to assessing, identifying and managing weight issues for HCPs require in-depth investigation. These (real or perceived) barriers need to be addressed in any future weight-related screening interventions. Developing a detailed understanding of child and parental perceptions is also crucial; priorities and expectations of all stakeholders will be vital to inform the development of any resources aimed at facilitating discussion of weight issues in spina bifida clinics. This will promote client/family engagement and optimize consultation time (62).

Overall, more research on this topic is urgently required to establish best practices, determine ideal clinical guidelines and draw this issue to the forefront of practice.
CONCLUSION

Weight and height are reportedly being measured regularly in spina bifida clinics across Canada, but practices vary and HCPs across disciplines expressed concern over the appropriateness of current assessment, classification and evaluation options for this population. Multidisciplinary teams are advocated for spina bifida care, but good team communication is required to ensure that children with weight-related issues do not inadvertently get overlooked. Clinicians report a number of barriers to weight-related discussions, including time available for consultations, child and parent engagement and clinician confidence. Specific skill training around weight-related issues and guidance on optimizing consultation time may improve clinician confidence and result in more effective discussions between HCPs, children and families.

ACKNOWLEDGEMENTS

The authors would like to thank all of the healthcare professionals who participated in the survey. This study was funded by The Spina Bifida and Hydrocephalus Association of Canada. The authors have no conflicts of interest to declare.
References


47. Walker W. Primary Care providers and medical homes for individuals with spina bifida. *Journal of Pediatric Medicine*. 2008;1:337-44.


### Overview of clinical practices reported by individual healthcare professionals

<table>
<thead>
<tr>
<th>Frequency of Practice</th>
<th>Weight assessed</th>
<th>Height assessed</th>
<th>Discussed with family</th>
<th>Children referred to specialist weight management programs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=46</td>
<td>(n=46)</td>
<td>(n=41)</td>
<td>(n=34)</td>
</tr>
<tr>
<td>Always</td>
<td>29 (63.0%)</td>
<td>12 (26.1%)</td>
<td>8 (19.5%)</td>
<td>0</td>
</tr>
<tr>
<td>Most of the time</td>
<td>11 (23.9%)</td>
<td>22 (47.8%)</td>
<td>19 (46.3%)</td>
<td>3 (8.8%)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4 (8.7%)</td>
<td>9 (19.6%)</td>
<td>12 (29.3%)</td>
<td>15 (44.1%)</td>
</tr>
<tr>
<td>Rarely</td>
<td>2 (4.3%)</td>
<td>3 (6.5%)</td>
<td>1 (2.4%)</td>
<td>12 (35.3%)</td>
</tr>
<tr>
<td>Never</td>
<td>0</td>
<td>0</td>
<td>1 (2.4%)</td>
<td>4 (11.8%)</td>
</tr>
</tbody>
</table>