

“I think people are just afraid to go there”  
Barriers and facilitators to weight-related discussions in a spina bifida  
context: Perspectives from children, families and health care  
professionals

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## ABSTRACT

**Background:** Children with spina bifida are at a high risk of having obesity, which has severe consequences for their current and future health. Early evidence suggests that weight-related issues are infrequently addressed with children with spina bifida. Moreover, we do not adequately understand the perspectives of healthcare professionals (HCPs) around this topic, or those of children with spina bifida and their families.

**Methods:** In-depth qualitative interviews were conducted with 13 multi-disciplinary healthcare professionals (HCPs) working in Canadian spina bifida clinics, 17 children with spina bifida and 20 of their parents. Experiences of barriers and facilitators for child participation in these weight-related discussions in spina bifida clinics were explored. Thematic analysis using a phenomenological approach was employed to analyse the data.

**Results:** Three themes were identified that characterized barriers to weight-related discussions: 1) Stigma; 2) Practice culture; and 3) Clinical systems. Five facilitators aided discussions related to weight: 1) Establishing rapport; 2) Building capacity; 3) Demonstrating empathy; 4) Sustaining motivation; and 5) Enhancing role clarity. HCPs had differing perspectives on engaging young people in weight-related communication, but many did not feel confident discussing the topic. Parents were concerned about HCPs discussing the child's weight with them in case it harmed their child's self-esteem. Children were happy to talk about weight-related topics with HCPs, but wanted them to acknowledge positive behavioural changes they had already made. Rapport between HCPs and the child was a significant facilitator to successful discussions, regardless of professional discipline.

**Conclusions:** There is a tension between parents' and HCPs' desire to address weight management at clinical visits and a fear of causing harm. Children and young people can be meaningfully involved in weight-related discussions in spina bifida clinics, but existing rapport between HCP and child is essential.

## BACKGROUND

Obesity is a global health concern and significantly impacts health services and quality of life [1-3]. Children and youth with disabilities have high rates of obesity [4], which can exacerbate their current condition and cause serious secondary conditions, such as pain, pressure sores, ambulation difficulties and social isolation [5-7]. This in turn limits their health and full participation in life [8, 9]. The issue is particularly salient for children with spina bifida, as they appear to have a unique set of interacting risk factors for obesity, including limitations in mobility, neurological impairments, altered feeding practices and restricted participation in physical and recreational activities [6, 10]. They have also been shown to have increased levels of body fat, decreased lean body mass and decreased physical fitness levels [11-15]. The prevalence of obesity in children 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 [6, 12, 13]. The consequences of obesity for those with spina bifida are severe, impacting ambulation, self-care activities, skin integrity and quality of life [5-7].

Healthcare professionals (HCPs) are encouraged to assess, monitor and discuss weight-related issues regularly with typically developing children and their families [16, 17]. However, evidence suggests that the assessment and discussion of children's weight by HCPs varies dramatically in practice [18-20]. Furthermore, HCPs report multiple barriers in communicating about weight-related issues with typically developing children and their families, reporting a lack of training [21, 22], fear of jeopardizing relationships with families [23-25], and a desire to "do no harm" given increased awareness of mental health, body image and eating disorders [21, 24, 26].

Despite the high risk of obesity in children with spina bifida, there is early evidence to suggest that weight-related issues and lifestyle behaviours (e.g. diet and physical activity) are addressed infrequently with children and families attending Canadian spina bifida clinics [27]. Since early interactions between HCPs and families can greatly influence children and families' receptivity to weight counseling [28, 29], it is imperative that discussions about weight-related issues are

sensitive and patient-centred [30]. An in-depth understanding of the barriers and facilitators to discussing weight-related issues from the perspectives of all stakeholders involved in consultations in spina bifida clinics would potentially enable greater supports to be provided to enhance clinical practice.

## **METHOD**

### *Design*

We conducted a qualitative interview study using a phenomenological approach [31], which is particularly well suited to understanding the meaning people ascribe to their real life experiences [32, 33].

### *Sample and recruitment*

#### Ethical approval

This study was reviewed and approved by the Research Ethics Boards at Holland Bloorview Kids Rehabilitation Hospital and Hamilton Health Sciences (covering McMaster Children's Hospital), Ontario, Canada.

#### Healthcare professionals

Purposive sampling [31] was used to recruit HCPs providing care to children in outpatient spina bifida clinics across Canada. HCPs were eligible if they provided any form of care to children with spina bifida, and included (but was not limited to) physicians, registered nurses, physiotherapists, occupational therapists, seating and ambulation aid specialists, orthotists and registered dietitians.

Invitation letters were sent via e-mail to clinic co-ordinators (or other key contact) at every spina bifida clinic in Canada (a total of 15 clinics). They were then asked to distribute the letter to all eligible members of their spina bifida team. Two reminder e-mails and one telephone call were made to the coordinator two weeks apart. Individuals contacted the Research Assistant (RA) if they were interested in participating in an interview and a convenient time for an

interview was arranged. Consent was obtained prior to interview. Some members of the research team participated as key informants, given their expertise in the field. We aimed to recruit 20 HCPs to provide a range of experience and disciplines.

### Children and families

Purposive sampling was also used to recruit children and their families attending spina bifida clinics at two large paediatric rehabilitation hospitals in Ontario, Canada (Holland Bloorview Kids Rehabilitation Hospital in Toronto and McMaster Children's Hospital in Hamilton).

Eligibility criteria were: a) aged 6-18 years; b) diagnosis of open neural tube defect (spina bifida aperta e.g. myelomeningocele) or closed neural tube defect (occult spinal dysraphism e.g. lipomyelomeningocele); c) able to communicate in English. Six years of age was selected as the lower age limit because children are becoming more independent from their parents [34]. Both clinics involved in the study provide care for children and young people up to the age of 18 years, establishing the upper limit. Parents were eligible if they were the primary caregiver for a child who was invited to participate in this study and were also able to communicate in English. Weight status (i.e. high body mass index) was not an explicit inclusion criteria for child or parent; however, in order to identify the experiences of those likely to be key informants [35], the clinic co-ordinators asked to identify children/families from lists of all eligible children attending the two spina bifida clinics who had expressed concern about past, current or future weight-related issues, or for who they believed weight-related and/or lifestyle issues may have been salient (e.g. self-reported poor dietary habits). The parent or child could take part even if the other chose not to.

Clinic coordinators at both hospitals mailed an information letter to identified children about the study. After giving one week to opt out of being contacted (a telephone number with voicemail was provided), the RA contacted them by telephone to answer any questions and establish if the child/family was interested in participating in an interview. As there is no age of consent in Ontario, consent forms were completed by children where they demonstrated capacity to consent (using a standard capacity assessment process). Where children did not

demonstrate capacity to consent, parents signed the consent form and the child was invited to sign an assent form. We aimed to recruit 20 children and their parents (i.e. 40 in total), again to obtain a range of experiences.

## Procedure

### *Healthcare professionals*

Healthcare professionals were mostly interviewed by telephone, unless they worked locally. Open-ended questions were asked, such as “How important is it to you to discuss weight-related issues in your consultations with children and families?”, “What are some of the challenges when having discussions about weight-related issues? What makes it easier?”. Participants were encouraged to provide examples and stories illustrating their experiences.

### *Children and families*

Children and families were interviewed in person at their chosen location, either at the child/family’s home or at one of the children’s hospitals. Depending upon family preference, children and parents were interviewed together or separately. Open questions, such as “Can you describe a typical clinic visit? “What sort of things do you usually talk about when you go to the clinic? , “Have you ever been weighed? ”Has anyone talked about your weight with you?” were used to sensitively explore families’ experiences of having weight-related issues and lifestyle behaviours discussed at spina bifida consultations. Questions were phrased in developmentally appropriate ways for children of different ages and cognitive ability.

### *Data analysis*

All interviews were professionally transcribed verbatim. Thematic analyses using a phenomenological approach [36, 37] were conducted on child, parent and HCP interviews in parallel. During analysis, data from children, parents and HCPs accounts were not explicitly linked to each other on an individual basis. Instead the aggregate of these accounts were used to provide context to explain the phenomena. These three lists of master themes were

examined separately but then carefully compared and contrasted to develop a nuanced understanding of the phenomena from multiple perspectives.

Two members of the team (ACM & TJK) with backgrounds in psychology read all of the transcripts. The transcripts were also divided up across the team so that all transcripts were read by three team members. The team represented expertise in developmental paediatrics, dietetics, nursing, physiatry, and psychology. All members had experience in paediatric rehabilitation. For confidentiality and by agreement with the whole team, the transcripts of team members interviewed were only reviewed by the lead author (ACM) and RA (TJK).

Team members met to discuss emerging themes and patterns around the barriers and facilitators to discussing weight-related issues. From these discussions, a flexible coding system was created, incorporating both deductive codes relating to concepts of priorities and perceived challenges (identified from the literature), and inductive codes to identify other concepts relating to the study aims. Following refinement through discussion, the final frameworks contained 29 codes for HCPs, 26 codes for parents and 26 codes for children's transcripts. The second RA (MP) then used these frameworks to code each transcript. All sections of text assigned the same code were then grouped into separate documents, from which a consolidated list of master themes was produced that illustrated patterns in the experiences participants recalled. These themes were then compared and contrasted, merged, divided or renamed as appropriate, and excerpts from the data used to support the final master themes.

Dissenting views and 'negative cases' were included where appropriate and the authors were careful that ideas from one participant or theme were not over or under represented [38]. Code-recode and peer examination, in addition to regular discussion among the authors about the process and the ideas emerging from the data helped to establish the trustworthiness of the findings [38]. Post-contact 'member checking' was not conducted as it was inconsistent

with the study’s interpretative paradigm [39]. An audit trail of key analytical decisions was documented throughout the data analysis.

**RESULTS**

A total of 47 participants were recruited: 13 HCPs, 17 children and 20 parents. The HCPs worked in spina bifida clinics in Ontario, Alberta, Nova Scotia and Saskatchewan, and represented a range of disciplines (see Table 1 for HCP characteristics). Time working with children with spina bifida ranged from 3 months to 31 years. We were unable to calculate the response rate as we do not know how many HCPs were sent the invitation by the clinic co-ordinators. Seventeen children (8 male, 9 female) and 20 family members (14 mothers and 6 fathers) were interviewed. Fourteen children were interviewed alone and 3 were interviewed with their parents. Two parents took part without their children (child demographic data is therefore missing for these two participants). One child participated without their parent. Children’s median age was 13 years (range 6- 18) and all but two participants had been diagnosed with myelomeningocele, the most common and severe form of spina bifida [10]. They represented a range of ambulation levels, which were classified according to Hoffer’s levels of ambulation [40]. Participants’ characteristics can be found in Table 2.

**Table 1-** Healthcare provider characteristics

<b>Discipline</b>	
<b>Dietitian</b>	2
<b>Registered nurse</b>	2
<b>Physiotherapist</b>	2
<b>Physicians</b>	5
<b>Social worker</b>	1
<b>Exercise therapist</b>	1
<b>Total</b>	<b>13</b>
<b>Province</b>	
<b>Alberta</b>	1
<b>Nova Scotia</b>	1
<b>Ontario</b>	9
<b>Saskatchewan</b>	2



**Table 2-** Characteristics of the child

ID	Age	Gender	Diagnosis 1	Ambulation level <sup>#</sup>	Interviewee
1	9	F	Myelomeningocele	2	Mother & Child
2	12	M	Myelomeningocele	4	No parent interview
3	15	M	Myelomeningocele	4	Father & Child
4	16	F	Myelomeningocele	1	Father
5	*	*	*	*	Mother
6	6	M	Myelomeningocele	1	Mother
7	*	*	*	*	Mother
8	17	F	Myelomeningocele	4	Father
9	10	F	Myelomeningocele	2	Father & Child
10	18	M	Myelomeningocele	1	Mother
11	16	M	Myelomeningocele	4	Mother
12	17	F	Myelomeningocele	1	Mother
13	15	F	Myelomeningocele	4	Mother & Father
14	8	M	Myelomeningocele	4	Mother
15	8	F	Lipomyelomeningocele	1	Mother
16	15	M	Myelomeningocele	2	Mother
17	18	F	Lipomyelomeningocele	4	Mother
18	12	M	Myelomeningocele	1	Mother & Father
19	13	F	Myelomeningocele	1	Mother

<sup>#</sup>For ambulation level, 1: Community ambulatory (walks indoors and outdoors); 2: Household ambulatory (walks only indoors); 3: Non-functional ambulatory (only walks during therapy sessions); 4: Non ambulatory (wheelchair bound)

\* Child did not participate (only parent) so demographic information unavailable.

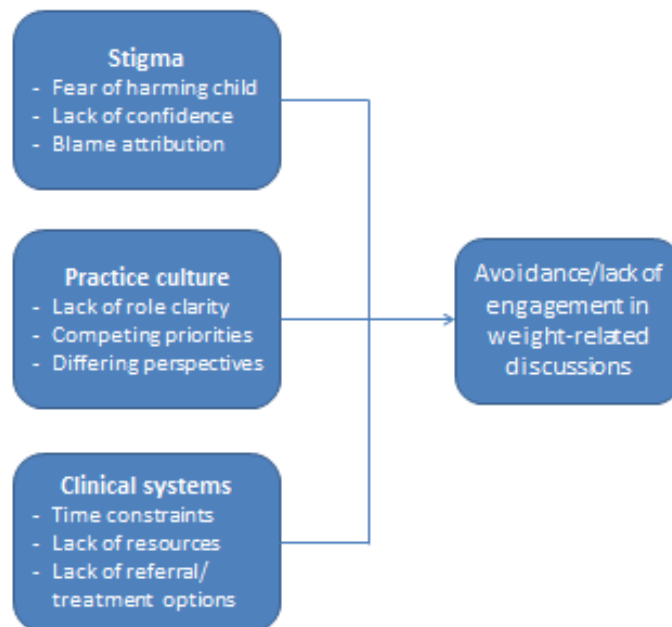
The data presented here are focused on the barriers and facilitators to engagement in discussions about weight in a spina bifida context. Three themes were identified describing barriers, namely 1) Stigma; 2) Practice culture; and 3) Clinical systems, all of which have subthemes (see Figure 1). Five main facilitators were identified by our participants, which are presented along with strategies to potentially enable those facilitators (see Figure 2).

## *Barriers to weight-related discussions with children, families and HCPs in spina bifida clinics*

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### THEME 1: STIGMA

The stigma associated with overweight and obesity was strongly reflected throughout the transcripts, both explicitly e.g. through talk of bullying, and implicitly, through unspoken reference to social norms and behaviour. Three main sub-themes were identified within this over-arching theme of 'stigma': a) Fear of harming the child; b) Clinician lack of confidence; and c) Blame attribution.



**Figure 1-** Barriers to weight-related discussions

*a) Fear of harming the child*

Although those parents interviewed had few concerns about their children being weighed and measured at clinic visits, they were concerned about whether the HCP should actually talk about weight to their child. Because of society's negative connotations around weight, parents were very sensitive about the potential harm of a weight discussion to their child's self-esteem; this was especially the case if parents themselves had experienced negative feelings about their own weight;

*"I don't think to talk about the direct issue of your weight [to a child] would be good... Because they end up like me [laughs]. Yes. Someone who is never satisfied, always trying, can never see the benefits, can never see the good of whatever it is they're doing, no matter how small it is, they keep on going, so they have esteem issues....So if you instill weight, if it's going to be about the numbers...so if you start at a young age talking about weight and numbers, I don't think that's really healthy." (Mother of Child #6)*

Parents tried to avoid the potential stigmatizing effects of focusing on weight and talked about being more concerned about how the child felt about themselves and working on that, than the weight itself, for example: *"I'm more concerned with how she feels about herself and working on that than the actual number of her weight"* (Mother of Child #5).

Healthcare professionals also spoke about being concerned that their discussions about weight might cause damage to the child or young person, and that this could influence how they communicated with the young person;

*"And just really that tightrope that you're walking with a young person's confidence, self-image, and just always trying to approach it in a way that they don't end up feeling they've been put down." (HCP6, Physician)*

HCPs talked about young people with spina bifida being a 'vulnerable population', due to their social, cognitive and physical challenges. Children of certain ages were felt to be especially prone to responding negatively to discussions about weight;

*"...we know that's it's such a very touchy situation...particularly with teenagers. And that's one thing that we avoid at any cost. Sometimes we cannot avoid it...we don't know how the patient is going to interpret the message. But that's one we think that we have always represented, not to be hurtful." (HCP10, Physician)*

In summary, the stigma associated with excess weight was highlighted by the fear of both parents and HCPs that discussing weight would negatively impact a child's psychological well-being.

#### *b) Clinician lack of confidence*

Due to the potentially negative impact discussions about weight could have on families because of the stigma associated with obesity, many HCPs did not feel confident discussing the topic unless families raised it first. For this reason, clinicians talked about how they negotiated around the topic of weight during consultations, describing themselves as 'dancing around it' and feeling nervous to address the issue. This could prevent some clinicians from mentioning it at all in consultations. Apart from potentially harming the child's self-esteem as discussed above, the other main concern that clinicians reported was the fear that talking about weight would negatively impact their therapeutic relationship with the client and family;

*"Because the last thing I'd want to do is say something and have the person I'm talking to shut down completely and not want to talk about it at all." (HCP5, Nurse)*

The main causes of this lack of confidence were a self-perceived lack of knowledge and/or training, especially around appropriate terminology and how to initiate discussions about weight. Because of this, some clinicians reported very rarely broaching the topic with families;

*“It’s kind of a loaded topic too for a lot of people...it’s not just to do with the child, it has to do with the whole family...I mean, it’s not really something that I was trained to talk about either and, I don’t always know, I mean, it feels delicate.”* (HCP3, Physiotherapist)

Willingness to approach the subject was evident, but a need for more information was identified around weight and obesity for children with spina bifida specifically, as many did not know how to initiate the conversation or discuss it in detail;

*“I think healthcare professionals need a, you know, health and weight 101 before they can engage appropriately in a conversation about it with somebody else...I mean, if you’re confident in what you’re talking about... and I don’t mean confidence in that you have to know anything and everything about the topic. But you at least need to know where to start.”* (HCP5, Nurse)

To summarize, many HCPs felt they lacked the training to discuss weight-related topics with children and families, especially those with spina bifida, and therefore often avoided it in case they negatively impacted therapeutic relationships with their clients. Although lack of confidence was clearly a priority topic for HCPs, it wasn’t identified by either children or their parents as a salient concern.

### *c) Blame attribution*

The stigma attached to overweight and obesity could make parents feel guilty and ashamed about their child’s weight. Some of the parents in our study talked about finding clinic appointments very stressful, especially when their child was weighed, in case their child had gained weight since their last appointment: *“I try my best that she does not gain weight. And I always [think] ‘Oh please, don’t gain weight’”* (Mother of Child#1). In some cases, this pressure was sufficient to prevent parents from attending clinic appointments. Indeed, clinicians reported that weight assessment could be a barrier to engaging in care, acknowledging that “I

*think being in the medical model of the hospital where they do focus on numbers...families feel ... judged, so I think that is a concern and a barrier.” (HCP13, Social Worker).*

Because parents perceived an increase in their child’s weight as a direct reflection of their parenting, they therefore had concerns about clinicians raising the topic with them in consultations:

*“I suppose it’s fine to bring up, but try not to make you feel uncomfortable about it I guess, like you know, not to blame , or make you feel guilty that maybe you weren’t looking after your child like you should have been. Like you’re just letting her eat whatever, you know, making you feel like it was your fault.” (Father of Child #8)*

Parents also perceived that clinicians dismissed the efforts they had already been making and did not adequately acknowledge the complex nature of weight loss in a child with a disability. Parents wanted HCPs to be empathic to the struggles they were experiencing with their child’s weight and acknowledge the efforts that the family were already making;

*“Talking to us about it is one thing and putting it into practice is a different thing. So the doctor shouldn’t feel like, “oh, the parents are not doing what we asked them to do,” because you might not understand what goes on behind the doors, right?” (Father of Child #9)*

This was corroborated to some degree by clinicians who acknowledged that the clinic environment could be judgmental toward the parents, the child and their environment;

*“I tend to, you know, probably put some judgments and looking at the parents and you know genetically, or you know lifestyle wise, this child’s really at risk of obesity and being overweight.” (HCP3, Physiotherapist)*

Conversely, some children and families felt that excess weight was an inevitable consequence of living with spina bifida, and therefore did not identify weight management as something that they had control over, which may have minimized the personal blame experienced felt;

*“Like, even if I’m overweight and people talk about, I don’t take it personally... Because, it’s just... like, normal for me, like, with my spina bifida.” (Child #3).*

All of our different stakeholder groups- children, parents and HCPs- identified that blame and judgment could be commonly felt in clinic situations when addressing children’s weight, in particular overweight or obesity.

## THEME 2: PRACTICE CULTURE

The second theme related to barriers comprised three sub-themes, all related to clinical practices and/or conducting consultations within a spina bifida clinic context. These were a) Lack of role clarity; b) Competing priorities; and c) Differing perspectives of child involvement in consultations.

### *a) Lack of role clarity*

HCPs spoke about the arbitrary way that weight was discussed within their clinic, and even between the different clients that they saw. A consistent approach was lacking and there was substantial confusion and differences of opinion over who would be the ‘best’ discipline to address weight within a spina bifida clinic. Colleagues from other disciplines were perceived to have greater influence, especially physicians;

*“Sometimes people don’t necessarily listen to other disciplines, where if you’re sitting in the room and there’s a doctor in there, they’re not going to listen to anything anybody says other than what that doctor tells them.” (HCP12, Exercise Therapist)*

Some HCPs perceived the need to repeat the message consistently to families, in order for them to understand the importance of the issue. Therefore, they suggested that all members of the team should raise the topic. Parents also raised the need for repetition as a possibility. There was no consensus among parents on the most appropriate clinician to discuss weight, although dietitians were often identified. More commonly, parents identified the need for a coordinated approach in the clinic:

*“...it’s a team thing and it’s all connected together, you know what I mean? For regards [sic] for a spina bifida child...I think it’s a team effort...” (Father of Child #4)*

However, the potentially negative consequences of multiple HCPs raising the topic of weight were raised by other clinicians;

*“I said to him, you know, “what do you think is happening with your weight?” ...and he just started to cry, and he said, “You’re the fourth person today who’s talked to me about my weight and, you know, there are other things about me...You don’t care about who I am, you just care about stupid things like my weight.” (HCP6, Physician).*

One solution to this lack of role clarity was for clinicians to wait for families to raise the topic themselves, or an assumption that another colleague would address it. However, families implicitly trusted that clinicians would raise the issue of weight if they felt that it was a problem for their child;

*“I’m assuming if they were concerned about his weight they would talk more about the weight management aspect of it, but they haven’t had to talk about it.” (Father of Child #4)*

The lack of role clarity when discussing weight-related topics was a barrier to both HCPs and families in spina bifida clinics, as it led to either no discussion of weight or too many



discussions regarding weight. Children did not express strong views about the who should talk to them.

### *b) Competing priorities*

It was evident from the data that clinicians, parents and children all had very different agendas going into a consultation, which could become a barrier to discussing weight-related issues. For example, some parents did not value regular weight discussions, preferring to focus on the child's feelings of self-worth instead. Even HCPs who rated weight as a priority topic to discuss in consultations did not always get chance to raise it if time was limited; issues such as bowel and bladder health were often identified as having greater priority. Weight often became a priority topic only when it was judged to be have a direct effect on the child's functioning. Because of this, clinicians (and parents themselves) often engaged children in weight-related discussions by linking the child's weight with their physical function, most notably the impact on the child's ability to walk. However, this message could potentially be perceived as intimidating and ineffective. For example, a parent recalled her child getting upset during a discussion about her weight with a clinician;

*"I don't think it was anything terrible, just a genuine motherly conversation, really, that she needs to think about her weight...and if she keeps that under control, it'd just be easier for her to keep walking **for the rest of her life.**" (Mother of Child #5; emphasis added)*

Children themselves commented on the function-related messages they received in clinic, and the negative effect that these messages could have;

*"I hear it all the time. You need to keep walking. You need to do this. You need to do that. I hear it all the time. So I get rather tired of hearing it." (Child #16).*

However, waiting for weight to become a problem was contrary to the view of many clinicians and parents who believed that prevention was a better approach than waiting for weight to become a health problem. Children also felt that HCPs shouldn't wait until weight became problematic;

*"I think it [weight management] should be talked about like, even if someone's obese or not, it should be talked about because to manage your weight is good for you to be healthy."* (Child #10)

In summary, all stakeholders came to consultations with their own priorities, which did not necessarily align and therefore could interfere with discussions around weight.

### *c) Differing perspectives on child involvement in discussions*

The participants in the study had varying perspectives regarding child involvement in weight-related discussions. Many parents felt that children should always be involved in conversations about the child's weight: *"For me, I mean, parents should know and the kid should also know. I mean, the child should also know about it, that she's overweight"* (Mother of Child #7).

Other participants felt that it was dependent upon the child's age, in terms of both level of understanding as well as developmental concerns. For example, it was thought that younger children may not benefit from weight discussions due to its sensitive nature and their limited ability to comprehend the social complexities associated with weight, although those above 10-12 years were often ready to engage in discussion;

*"But if [the child] is ten, twelve [years] and up, I think they are ready to talk to individuals and communicate what they feel what they can do and, by themselves and maybe that will be something that will help."* (Father of child #9)

Children in different developmental stages were considered to be receptive at different times. For example, one mother felt that her teenage son was currently very unreceptive to health

promotion messages and that the messaging may have had more impact when he was younger. Other parents talked about a gradual transfer of responsibility as the child became older and more able to take on self-management of his or her condition;

*“I think that’s a good thing [to talk directly to her] because it’s her body. She’s the one who needs to take care of it now...so I think the transition over the years to speak to her directly and to treat her like an adult at this point in time is a good thing.”* (Mother of Child #12)

This also reflects clinical practice, whereby parents are often asked to leave the room once their children become a teen so that they had an opportunity to speak to the HCP alone. Nevertheless, parents and children reported relying on HCPs to be able to judge whether the child wanted to be included in the discussions: *“Maybe have a feel for how the person takes the information and whether they’re wanting to be involved in the conversation”* (Mother of Child #5). Many HCPs also used this approach, reporting that they took their lead from children, in order to provide client-centred care.

HCPs also reported an inclusive approach to weight-related discussions, describing them as *“a family project. It’s not only a one person project. It’s everyone involved”* (HCP10, Physician). This could include extended family members, if the child spent significant time with them.

Children themselves wanted to be involved in conversations and to be heard by HCPs, advising them *“to hear the other people [child] out I guess, to hear what they have to say”* (Child #8).

The differences in HCPs’ approaches to weight were also noted by the children, when asked to describe how the HCPs they saw discussed the topic of weight;

*“Completely depends on who’s doing it. Some days they’re very skipping [sic] and some days they’ll tell you straight up you need to work on this, this, this, and this...All depends on who you’re dealing with, which doctor it is”.* (Child #16)

Children, parents and HCPs therefore all came to consultations with differing expectations of child involvement.

### THEME 3: CLINICAL SYSTEMS

The third theme describing barriers to weight-related discussions comprised three sub-themes, which all referred to system-related issues that impacted clinical practice: a) Time constraints; b) Lack of resources; and c) Lack of referral/treatment options.

#### *a) Time constraints*

Time constraints within the busy clinic context affected whether weight-related issues were discussed, regardless of the HCPs comfort in having a weight-related discussion. HCPs often did not feel that they had time to discuss everything they wanted to, and that it would be especially prohibitive for every team member to talk about weight in their particular consultation, as others had suggested. These time constraints resulted in HCPs having to prioritize topics to discuss, even when weight was a significant issue for that family;

*“If I see a really, like a child who’s clearly overweight, then I may discuss with them in more detail, I may discuss more around diet and caloric intake, but if I’m in a time crunch, the big issues are gonna be bladder, bowel, and then school if they’re older.”*  
(HCP8, Physician)

Similarly, lifestyle behaviours such as diet and physical activity were often low on HCPs’ priority list when consulting with families;

*“I’m not going to prioritize any one thing in particular, until I know what the family’s issues are. And if they don’t have anything then sure I’ll cover recreation. But if they come in and I’ve got 15 minutes and their problem is a wound or you know, I have to address that first.”* (HCP7, Physiotherapist)

The limited time allotted to consultations within the clinics meant that all stakeholders had to limit the topics to address, and often weight was lower down the agenda than other matters (see also ‘competing priorities’).

#### *b) Lack of resources*

Healthcare professionals were keen to have resources to support them in discussing weight with parents and children, especially those that were visual. Many described using growth charts, although there was varied awareness about how applicable these growth charts were to children with spina bifida, given that currently available versions were developed only for typically developing children. Having a resource or tool that was specific to spina bifida was greatly desired for two reasons: first, to help children and families identify weight as an issue;

*“...we show them on a chart where their child’s weight should be and where theirs is. And showing them the different risks involved with having a weight in this particular category, and it kind of opens their eyes a little bit...”* (HCP12, Exercise Therapist)

Second, they desired some form of visual to help the parents and children track their progress over time; *“We don’t have any resources at our fingertips to kind of aid them along that journey”* (HCP5, Nurse). Canada’s Food Guide was also used in conversations, usually to signpost children and families towards a source of information on healthy eating, although no HCP talked about reviewing it in detail with the families. The need for tailoring the resource to kids with spina bifida (with their typically lower need for caloric intake) was raised as a barrier to being able to provide individualized advice, along with a lack of knowledge on the HCPs part.

Parents endorsed the need for tools, especially visual tools that would aid their own and their child’s understanding. As with the HCPs, parents felt that children could be sensitized to the importance of weight management using visual means to portray the potentially serious consequences of obesity, such as in a video. Parents also felt that using a visual growth chart could initiate a conversation about weight;

*“I think with [CHILD], putting her on that spectrum and putting her on the graph and showing her the graph and how’s she’s grown and what a normal growth is and what her growth has been, I think that opens up conversations and I think kids will ask questions from that. But I think you need to do it in a very kind way.” (Mother of Child #12)*

Children also wanted a visual way of tracking their progress, citing charts as providing motivation and feedback that they could then act upon. Without these resources, discussions of weight became more abstract and made it harder to engage children and families meaningfully.

### *c) Lack of referral/treatment options*

Many HCPs reported having little or no dietitian support in their spina bifida clinics, and had few referral options for specialized weight management services. HCPs felt keenly that they didn’t have the time or training to address weight directly and therefore, were reluctant in identifying a problem that they could not resolve;

*“I might help a young person get motivated to lose weight or to not gain weight. But when, you know, when there’s no dietician on the team and there’s no, when I don’t know where to refer them to where they can be physically active in their chair, then, that makes it more challenging.” (HCP6, Physician)*

This was also acknowledged from the parental perspective, as they expressed significant frustration when HCPs identified the child’s weight as concerning or problematic, but no help was provided (or perceived to be provided). Parents were even willing to pay for specialist services but were unable to locate any;

*“I’d like to know where there’s a camp that I can send him to because I don’t even know what the next step even is. Like, I mean, he needs to go somewhere where it’s drastic to*

*get this weight off and get it off as quick as possible... Like, I don't care the cost of it. If you guys told me it was a few thousand dollars, I wouldn't even care.” (Mother of Child #11)*

In summary, faced with a lack of options for spina bifida- specific weight-management services, some HCPs refrained from discussing the topic. This reflected families’ frustration when concerns were identified but no follow-up care provided.

### *Facilitators to weight-related discussions with children, families and HCPs attending spina bifida clinics and strategies to promote engagement*

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Facilitators to engaging in positive discussions around weight-related topics were identified by all stakeholders, as well as strategies that could potentially enable those facilitators (see Figure 2).



**Figure 2-** Facilitators to weight-related discussion and strategies to promote engagement

### *a) Establishing rapport*

To engage children and facilitate their meaningful participation in consultations, rapport was critical. Most parents and children did not have strong preferences around what discipline should talk about the subject, as long as there was rapport between child/family and HCP. To build rapport, a trusting relationship was required, where the family felt that the HCP understood their child. This was often achieved through questioning about child-related activities;

*“There’s always interactions and more play with the [younger] kids, and then as I get to know them and they’re able to talk, I would interact with them maybe more, asking them more questions about how they’re doing in school and what they’re doing for fun, for recreation, just to kinda develop a rapport with them.”* (HCP13, Social Worker)

Parents and children both appreciated HCPs taking the time to understand their child’s interests and identifying what engages them, otherwise building rapport and developing a trusting relationship would be extremely challenging;

*“So his real loves are, you know, sports and construction and that kind of stuff. And I find most of the professionals have picked up on that. And sometimes some of them haven't and then they wonder why he doesn't talk. Well, there's a reason, you know.”* (Mother of Child #14)

Children themselves also welcomed the HCP building rapport before going into weight-related discussions;

*“Like we talk about other topics too, like what goes on at school and stuff, and then we get into the topic [weight]. But it’s eased in. So it’s not directly to that. It’s kind of like gaining the person’s interest sort of thing.”* (Child #4)



Therefore, establishing rapport and trust was perceived as facilitating discussions about weight-related topics through the development of a trusting relationship.

### *b) Building capacity*

To promote clinician confidence in addressing weight-related topics, specific training was desired by HCPs. Many HCPs wanted more knowledge upon which to draw when talking to children with spina bifida and their families about weight;

*“I think we need more workshops maybe like how to help those children with obesity challenges, yeah, just to know how to address the issues and have more concrete, like to give them... it’s always great to have updates and more recent approach on how weight management is, like, what works for them for weight management.” (HCP4, Dietitian).*

Using growth velocity over time was a strategy successfully used by some HCPs, rather than categorizing the child’s weight status based on a one-time measurement. This somewhat removed the problem of using growth charts designed for typically developing children;

*“Like I show them the growth chart and show them where we should be trending towards, so it’s really then depending on the history, so we don’t really like compare it to the average necessarily but to the individual, it’s really telling that the growth velocity a bit higher than we desire.” (HCP4, Dietitian).*

### *c) Demonstrating empathy*

Many parents reported struggling with their child’s weight and wanted HCPs to be empathic to these struggles and acknowledge the efforts the family were already making. Acknowledging the difficulties experienced by parents could significantly reduce their stress and promote a better therapeutic relationship;

*“But it’s just, it’s just hard hearing it...you gotta understand, when you look at your child, it was very hard for myself when [CHILD] was much overweight.” (Father of Child #4)*

Similarly, children wanted understanding and patience from HCPs, and to have their efforts acknowledged;

*“I don’t like when people nag me... using this angry tone at me. I’m like ‘you can stop. I’m trying. You need to have patience’...” (Child #16)*

Some HCPs understood the challenging nature of weight management in children with spina bifida and reported being encouraging even for small changes. This type of empathic approach was greatly appreciated by children and families.

#### *d) Sustaining motivation*

Given the difficulty of engaging in positive lifestyle behaviours for some families, parents and children spoke about the need for sustained motivation, which could be facilitated by HCPs. Focusing upon negative behaviours rarely facilitated positive change; instead parents and children wanted HCPs to be optimistic;

*“Probably because the child I guess realizes that they have a disability and they feel that the, they can’t do the things like other children do. But it’s very important for the parent or the doctor to keep, to say, say keep them pumped up. Like, ‘you know what? You can do anything you put your mind to,’ right?” (Father of Child #4)*

Children agreed that they benefited from HCPs taking an optimistic, strengths- based approach highlighting what the child could do, rather what they couldn’t do or should stop doing;

*“I think they should like ask the person what they like to do in terms of physical activity and like what they like to eat, and then based on that, what they should do if they need*

*to like, do anything to improve, instead of just saying that everything that they're doing is not good..." (Child #4)*

HCPs also emphasized the importance of reinforcing positive behaviour from a health promotion perspective, even when the child's weight was not at a concerning level:

*"If they have a healthy weight, we still go over the chart and say 'what you guys are doing is obviously good.'" (HCP12, Exercise Therapist)*

Therefore, a strengths- based approach was desired by children and families, and HCPs reported that it facilitated positive discussions around weight.

#### *e) Enhancing role clarity*

Given the confusion caused by unclear stakeholder roles, good communication among clinical teams was considered key. This ensured that any weight issues were not overlooked, and that individual team members' strengths could be utilized to provide optimal care. This could also boost HCPs' confidence in weight management;

*"Well, it's easier for me when I know I've got backup. So that I can talk to others, it makes it easier knowing that you've got, a multidisciplinary team around you that can provide much more specific help... So the more people there are on the team who are, you know, knowledgeable and have resources around these things, that really makes it easier." (HCP6, Physician)*

Enabling parents and children to engage in their preferred role was also a facilitator to engaging in open communication about weight-related matters, as well as empowering them to express their wishes;

*“I think it’s having a team approach, and for each kid picking out one or two people they’re going to talk to so that you don’t end up in a situation like I did with that kid in a different clinic who was in tears because I was the fourth person who had talked to him that day about his weight.” (HCP6, Physician)*

Taking an open approach could empower children and families, and potentially enable them to speak up if they did not want to discuss the topic of weight with that person;

*“I think that at that point it’s up to the parent or the child to say that they don’t want to hear it from that certain person again. Like the child has to speak up for themselves, that’s all.” (Mother of Child #5)*

Clear roles within clinical teams, as well as enabling children and families to play roles they felt comfortable with therefore greatly facilitated child- and family-centred consultations about weight.

## **DISCUSSION**

This study is the first to examine weight-related discussions between HCPs, children with spina bifida and their parents. Exploring the perspectives of multiple stakeholders allowed us to develop a nuanced understanding of this complex phenomenon, and identify barriers and facilitators to positive weight-related communication.

Three overarching themes were identified that characterized the barriers to engagement in weight-related discussions: stigma, practice culture and clinical systems. Significant stigma associated with obesity is evident throughout society broadly [41], and this was reflected in parental and HCPs’ reluctance to address the issue with children, in case it negatively impacted the children’s self-esteem or ruined therapeutic relationships.

However, children and families also acknowledged that weight was an important aspect of health and well-being that should be addressed; they trusted HCPs to raise the issue if it was a concern for their child, but HCPs often waited for parents to raise it. There is a risk, therefore, that weight and lifestyle behaviours remain unaddressed in spina bifida consultations as everyone waits for someone else to raise it.

Spina bifida is considered “the most complex congenital abnormality compatible with long-term survival” [42](p114), and this was highlighted by the large number of medical and psychosocial issues addressed during the clinic appointments. Weight and obesity were often lower down the agenda than other topics such as continence and mobility, and were therefore reportedly addressed less frequently, especially when there were time-constraints.

Many of the barriers we identified, such as lack of time, confidence and a fear of harming children’s self-esteem agree with findings in the literature from clinicians who work with typically developing children [43, 44]. However, the risks are potentially greater in children with spina bifida: their health and even their life may depend upon seeing HCPs regularly [45], so concerns about damaging relationships with families are understandable. Furthermore, children with disabilities are already stigmatized [46], which can be compounded even further by the stigma of having obesity.

Parents and children were clear that establishing rapport and demonstrating empathy were critical to a positive discussion about weight. These facets have been reported as important for satisfying paediatric rehabilitation services generally [47], but are arguably even more important in weight-related discussions given the sensitive nature of the topic and potentially stressful circumstances. There is great potential for the breakdown of therapeutic relationships when HCPs perceive parents and children to be ‘non-compliant’ with weight management and lifestyle advice, and families feel that their efforts and the complexity of the situation are not being acknowledged. However, children were happy to receive positively-framed messages, tailored to their circumstances and abilities.

Healthcare professionals, children and parents all agreed that visual tools could enhance understanding and engagement around weight, as well as facilitate easier discussions. In particular, many HCPs discussed the great need for standardized tools for measuring the growth of children with spina bifida specifically, recognizing that plotting body mass index on growth charts designed for typically developing children is inappropriate and potentially misleading [13, 48].

### Strengths and limitations

This study helps us better understand the drivers, barriers and facilitators to positive weight-related discussion in children with spina bifida and their families, who are at a high risk of obesity. We engaged HCPs from a range of disciplines currently engaging in clinical practice in Canadian spina bifida clinics, the majority of whom had extensive experience working with children with spina bifida. Children with a wide age-range and ambulatory status also participated along with their parents, offering multiple illuminating perspectives.

Our study does have some limitations, however. We were unable to calculate a response rate from the HCPs as we do not know how many invitations were distributed by clinic coordinators. There was also uneven coverage across Canada, with HCPs predominantly practicing in Ontario, including some of the team members. We were also unable to recruit our target of 20 HCPs, although the team felt that saturation had been reached with 13 interviews. There was also uneven coverage of data across different stakeholders- in particular, contributions from children and young people were limited, and one sub-theme ('lack of confidence') consisted entirely of one stakeholder group (HCPs). It is important to note, however, that children and parents did have the opportunity to comment, but other issues were more salient to them.

### CONCLUSIONS

This study identified a great deal of uncertainty and inconsistency in weight-related consultations between HCPs, children with spina bifida and their families. There is a tension between parents' and HCPs' desire to address weight management at clinical visits and a fear

all round of causing harm to the child's self-esteem. We therefore need to normalize these discussions in order to reduce the associated stigma and fear. Children and young people actually desire to be meaningfully involved in weight-related discussions, but existing rapport between HCP and child is essential. Facilitating positive experiences is therefore key. In order to enhance the high quality care HCPs already provide to children and families attending spina bifida clinics, we need to develop a consistent approach, teach appropriate skills and build confidence around weight-related communication. Developing appropriate resources and support will be a critical part of this process.

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