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ORIGINAL ARTICLE

"It's not a simple answer." A qualitative study to explore how healthcare providers can best support families with a child with autism spectrum disorder and overweight or obesity

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ABSTRACT

Purpose: This qualitative study aimed to explore the experiences of parents supporting their child with Autism Spectrum Disorder (ASD) and overweight or obesity (OW/OB), including their weight management support needs.

Methods: Interview transcripts were analysed using inductive thematic analysis. Nine parents ($n = 9$ mothers) of ten children with ASD (7 males, 3 females) participated in individual semi-structured interviews.

Results: The three themes developed were: (1) Our journey to obtain weight management support; (2) I need real-world solutions; and (3) The what, who and how of our weight management needs. Parents reported being proactive in seeking weight management support for their child but were disappointed with the services offered. Resources were not tailored to the child's complex nutrition and behavioural issues or their abilities and functioning. A multidisciplinary approach that integrated both disability and weight management expertise was desired, but not experienced. A range of formal and informal programs were recommended.

Conclusion: This study provides a call to action for supports that ensure children with ASD and OW/OB receive integrated, individualised support to maximise their health and wellness.

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Autism spectrum disorder; obesity; weight management; parent; nutrition; health promotion

➤ IMPLICATIONS FOR REHABILITATION

- Children with autism spectrum disorder (ASD) are at high risk of developing overweight or obesity.
- The weight management support needs of parents of children with ASD and overweight or obesity are not being met.
- Support must be tailored to the child's needs, which are often complex.
- Health services that integrate expertise in both disability and weight management are needed for children with ASD and their families.

Introduction

A foundation of health and wellness enables children and young people (herein children) to participate in daily tasks and activities [1]. Habitual physical activity and healthy dietary intakes can help promote good health [2], yet children with disabilities report lower physical activities, higher sedentary activities, and poorer quality diets than their peers without disabilities [3,4]. They are also 2–3 times more likely to be classified as overweight or obese (OW/OB) than their typically developing peers [5,6]. Although higher weights do not automatically confer poor health [7], children with disabilities who have weight concerns may experience a range of secondary conditions and challenges with activities of daily living [8,9]. Parents of children with disabilities face a number of constraints that can impact their children's weight management. For example, they often experience challenges and barriers accessing mainstream health promotion and/or weight management programs [10]. Parents also experience time constraints and competing priorities, which can be exacerbated by routines that often include multiple medical appointments and specialized therapies [11,12].

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by impairments in social cognition, social communication and understanding relationships, as well as repetitive behaviours that affect 1-in-54 children [13,14]. Children with ASD experience a number of risk factors that can contribute to OW/OB and they have been found to have higher weights than children without ASD [15,16]. Risk factors include coordination difficulties, which makes physical activity challenging [17]; social

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isolation, which reduces opportunities to be physically active with peers [18,19]; increased food sensitivity and specific food selectivity [20], which can lead to higher consumption of low nutrition and energy-dense foods [21]; and medications that include weight gain as a common side effect [22]. They may also have genetic and neural differences that impact energy regulation, predisposing them to higher weights [15].

According to the World Health Organization, OW/OB in childhood cannot be addressed without considering the context of the environment in which the child is immersed [23]. Indeed, parents have a substantial impact on children's health and wellness [24] and can empower change within their families [25]. Given the opportunity to voice their concerns and provide feedback, parents can have a positive effect on paediatric weight management [25,26].

Although parents of children with ASD have previously described some of the challenges of weight management for their child [20], there is little known about what supports parents of children with ASD would find helpful. To ensure that effective health services and supports best meet the needs of this high-risk population, it is critical to understand parental perspectives around their child's weight management experiences. Therefore, the aim of this qualitative study was to explore the experiences of parents supporting their child with ASD and OW/OB as well as their weight management support needs.

Methods

Design and approach

The research reported here was part of a larger, national team grant focused on obesity in children [27]. A qualitative inquiry employing individual interviews was used to conduct this study, given its suitability for exploratory research objectives [28].

Participants and setting

Participants were primary caregivers (herein 'parents') of children with ASD who were accessing outpatient services at a large, urban rehabilitation teaching hospital that provides care for children and young adults with physical and neurodevelopmental conditions. Within the hospital, the psychopharmacology clinic provides care to 2–18 year-olds with a neurodevelopmental disorder who have been prescribed psychotropic medication(s) for a specified behavioral issue. Atypical antipsychotic medication is commonly prescribed, in addition to behavioral advice (e.g., around sleep, communication techniques). The Canadian Alliance for Monitoring Effectiveness and Safety of Antipsychotics in Children guidelines are followed (see http://camesaguideline.org), which includes the recommendation for healthcare providers to monitor any metabolic complications of antipsychotic medications, including weight gain.

Recruitment

Following research ethics approval, a research nurse in the psychopharmacology clinic mailed information letters to parents inviting them to participate in the study. Those attending the clinic in person with their child were given information letters and asked for permission for the researcher to contact them. Parents were eligible to participate if their child had a body mass index (BMI) $\geq 85^{th}$ percentile (i.e,. classified as overweight or obese [29]) and a confirmed diagnosis of ASD as per the Diagnostic and Statistical Manual of Mental Disorders criteria [13], and the Autism Diagnostic Observation Schedule [30]. Parents also had to communicate in English.

Data collection

Semi-structured individual interviews were conducted to understand parents' subjective experiences regarding weight management and their child with ASD. The interview guide was developed using previous literature and augmented by the expertise on the multi-disciplinary team, which included health psychology, nutrition, endocrinology, and paediatric rehabilitation. However, while the interview guide included a number of issues of interest, it was also flexible and allowed parents to talk about what was most important to them within the broad framework of weight management and their child with ASD in order to access rich data [31]. As with other exploratory research, the data collection approach did not align with any specific theoretical framework [32,33]. Interviews took place in the parent's home. Once informed, written consent was obtained, the parent was given a short family demographic questionnaire to complete and then participated in an interview that lasted approximately 60 minutes. Sample interview questions can be found in Table 1.

Data analysis

All interviews were audio taped using an encrypted digital voice recorder and transcribed professionally. Transcripts were then checked by the interviewer to ensure accuracy between the audio recording and transcript. Participants were assigned pseudonyms before analysis. Based on the analytical insights of Clarke & Braun, inductive thematic analysis was used to identify, analyze and report patterns of meaning in the qualitative data [34]. The lead author (ACM) read all transcripts to become familiar with the data and the other authors each read a selection of transcripts. The research team then discussed emerging ideas and patterns in the data. The lead author then re-read the transcripts, generated codes and applied them to commonly occurring units of meaning within the data set. Through a process of sorting, organizing and refining, the codes were collapsed into larger themes across the data set. These codes were then grouped together, and an overarching label applied. These groupings became themes, which reflected patterns of shared meaning around a concept [35]. Once the themes were developed, each one was re-examined to ensure that data within themes were coherent and there were distinguishable differences between themes [34]. Sub-themes were smaller groupings of codes that related to the overall theme but were expressed in different ways [36]. Data analysis was considered complete when team members considered the main theme and subthemes to be coherent and distinctive, and all inconsistencies identified and resolved [37].

Table 1. Examples of interview questions.

Interview questions
• What are your health and wellness goals for your child and broader family?
• Tell me about your experiences of speaking with healthcare providers about your child's weight and wellness.
• What supports or services were you hoping your child was going to receive as a result of that/those conversation(s)?
• What should be considered when designing weight management supports for children with ASD?
• What do you think would most help other children with similar abilities to your child and their families with weight management care?

Methodological rigour and trustworthiness were enhanced by a thorough, inclusive and comprehensive coding process, regular team discussions about the process and the ideas identified in the data, and considering negative cases [34,38].

Results

The study included nine parents ($n = 9$ mothers) of ten children with ASD and OW/OB (7 males, 3 females). Eight parents self-reported being of European Caucasian origins and one of South Asian origin. Six had university-level education, two college-level and one other (parent did not provide more details). Our analyses led to the generation of the following three complementary and distinct themes: 1) Our journey to obtain weight management support; 2) I need real-world solutions; 3) The what, who and how of our weight management needs.

Our journey to obtain weight management support

Parents reported their experiences from becoming aware of their child's increasing weight, approaching their healthcare providers (HCPs) to seek guidance, to receiving some form of advice on weight management and/or health behaviours for their children with ASD. There were three sub-themes within this theme: *I tried to be proactive; Early experiences were encouraging; Weight management supports were ultimately disappointing*.

I Tried to be proactive

Parents described becoming aware of their child's weight challenges as they got older, particularly when other members of their family lived in larger bodies, which appeared to sensitise them to their child's increasing weight. Looking ahead to their child's adult years also appeared to enhance parents' awareness of their child's weight while in childhood, and their feelings that they needed to do something about it;

> *You know, my family is big, kind of like my whole side of the family, all the people are overweight, and if they aren't while they're young, they certainly are by the time they are middle-aged. So it's something I would say my kids are pre-disposed to, so I appreciate getting on top of it* (Miyu, mother of 14-year old boy)

However, even when parents were aware of potential issues with their child's weight, they did not have the tools to address their concerns. They therefore sought support from HCPs, rather than waiting for a healthcare professional to raise the topic;

> *We're seeking the support, we want it so it's not like we're going in and people are saying to us 'he needs to lose weight'* (Megan, mother of a 12-year old boy)

As Megan indicates, parents reported proactively seeking support for their child's weight management from the healthcare team that the parents and child saw regularly, which usually included a physician (e.g., developmental paediatrician, paediatric neurologist, community-based paediatrician). Although demonstrating readiness for professional input, parents reported that they often had to take the initiative and make multiple requests for support, described here by Miyu: *"I did have to request the nutrition clinic and then every time we go back, I have to request it"* (Miyu, mother of 14-year old boy).

Early experiences were encouraging

Some parents reported HCPs in their immediate healthcare team being open-minded and responsive when they raised their concerns, both about their child's weight and also their broader health behaviours, such as being physically active. In one case, a parent described their HCP taking a holistic approach to their child's health and wellness;

> *Our health care provider would really like [child] to lose some weight and she would really like him to do more exercise. She has never made him feel bad or talked to him about, you know, never has even said "[Child] you have to lose weight". It's more like "*[Child], I want you to exercise" (Abby, mother of 13-year old boy).

Open-mindedness and clear communication were also reported (and praised) by other parents, which made them feel they could approach them with concerns. Other parents also reported that the HCPs they raised their concerns with were willing to support their referral to more specialist care;

> *"The people like Dr. X at the Y Clinic was great. I mean, she said, yes, we'll get him right in, and so that was a nice support"* (Lena, mother of a 14-year old boy)

Weight management supports were ultimately disappointing

Once parents had raised their concerns to their immediate healthcare team, their child was typically referred to speciality services, usually a nutrition clinic. There was collective hope (by both parents and their healthcare team) that this would bring benefits for the child and family. However, many parents reported feeling disappointed with the specialist service, which was typically a tertiary nutrition clinic led by a physician and clinical dietitian. Parents were pleased to have been referred to experts, but then felt deflated when the interaction was perceived as perfunctory, and they were given information that was already publicly available;

> *So, we didn't really have a very positive interaction. Essentially, the doctor, you know, got out the callipers, and weighed him, and took his vitals and all of that, and said, yes, he's obese, and here's the Canada Food Guide, you know? So that's basically what we've had, yeah* (Lena, mother of a 14-year old boy)

Few parents felt that they had received any novel information that would help them address their child's weight challenges, although they perceived some differences between disciplines (e.g., physician and dietitian). However, the disappointment in the services remained for families;

> *I felt like the dietician had more kind of ideas, and more positive things to say, versus just kind of the… the numbers, and disappointment* (Miyu, mother of 14-year old boy)

I Need real-world solutions

Parents needed tailored solutions that recognized their unique situations, in order to address their child's weight management challenges, although these types of solutions were rarely received. The two sub-themes were *It's a juggling act* and *It's not a simple answer.*

It's a juggling act

Parents reported complex and often stressful lives, managing the many different facets of their child's condition as well as family life. Eating times were often challenging due to their child's behaviour around food, which could become disruptive if they were asked to eat foods with certain tastes or textures. Ultimately, keeping their child calm was a higher priority for parents than forcing them to eat food with high nutritional value;

> *And, I mean, at what point are you going to sit there and set your kid off banging their head over string beans. Like – like juggling. Like you just –*

at what point is a concussion worth eating string beans? (Sarah, mother of 10-year old girl)

Parents discussed the pressure of caring for their child with ASD and reported feeling overwhelmed when considering additional nutritional advice on top of their existing daily pressures. While parents understood and valued the need for good nutrition, priorities around family functioning often superseded this. There was therefore some ambivalence towards enacting weight management strategies in the home given the other stressors they were experiencing;

[Talking to the nutritionist] was stressful. I did feel like it's just another thing to worry about … although it's important to keep in mind, and I think it's a valuable thing for us to keep an eye on, obviously, and do what we can, but it definitely is another stress … we're already doing so much with her, like how much more can we [do] … Sometimes I feel like it's a losing battle (Alex, mother of 16-year old girl).

Parents therefore felt that it was important for HCPs to acknowledge the considerable responsibilities parents face caring for a child with ASD, so that realistic plans could be created that fitted their real-world needs.

It's not a simple answer

The primary support need reported by parents was information that was tailored to their child's particular situation. Parents understood that weight management was not easy for *any* child but wanted information that was tailored to their child with ASD. Given that children with ASD often have idiosyncratic eating preferences relating to the taste, texture, smell and colour of different foods, many parents struggled to find foods that their child would eat. Therefore, their support needs extended beyond the standard dietary information that was typically provided (e.g., Canada's Food Guide). For example, advice to increase fruit and vegetable intake was not considered helpful when their child had extremely limited food preferences;

I love how they slap down the Canada Food Guide in front of me and said … this is everything you need to know. Well, guess what … what are you going to do when my kid goes seven days without eating, on strike, because she's not going to eat anything on that paper? You … it's not a simple answer. Like, you need to individualize things to each child (Sarah, mother of a 10-year old girl)

An additional difficulty parents faced when implementing recommendations from medical professionals was the training approach that they had previously been taught to effectively shape and manage their child's behaviour. Specifically, Miyu discussed her prior training in Applied Behavioural Analysis (ABA) and related it to the current challenges she experienced getting her child to eat healthy options; *"ABA uses edibles for reward, right? I clearly use food as a distraction"*, highlighting that changing established and effective reward systems away from food was extremely challenging and confusing for a child. Acknowledgement by HCPs of this had been missing in her experience, saying that *"[HCPS should] try to understand that our life is what it is"* (Miyu, mother of a 14-year old boy).

The what, who, and how of our weight management support needs

Participants made recommendations that they believed would be helpful in supporting children with ASD and their families around weight management. Recommendations were grouped into three sub-themes: *Formal and informal strategies are helpful*; *We need a team approach*; and *Connections are important.*

Formal and informal strategies are helpful

Parents suggested a range of different strategies that they felt would support them and their child. A coaching model with one-to-one support was considered ideal by many parents, who believed that this would make it easier to tailor the support to their child's cognitive and physical abilities. For example, Miyu described what she thought an ideal coaching model should look like for her son;

Maybe a young male who would come out and spend a few hours a week with him, doing healthy activities together, you know, getting him involved in some kind of sports … somebody like a healthy big brother, or something, who would spend time with [child], helping him make good choices, and doing kind of active things with him, and helping him learn to enjoy active things (Miyu, mother of 14-year old boy)

However, given the complexity of their child's condition and other commitments they needed to manage on a daily basis, some parents desired a more structured program to address their child's weight management needs. Having inclusive places for children with ASD to engage in structured physical activity was deemed important, because parents felt that their children were excluded when attempting to join groups attended by typically developing youth;

You know some kind like exercise place, disability kids go there like yoga class, these things. Because everywhere no ask, Your autistic children? Okay, no, no. Here is normal kids. Maybe your kids no comfortable here (Abana, mother of a 14-year old boy and 13- year old girl)

We need a team approach

Parents felt that their child's weight management challenges needed the expertise of more than just one HCP, ideally a multidisciplinary team including both disability and weight management expertise;

It's a team approach. It's not just one person, it's a group of people who have that common interest in helping children with disabilities and their weight management just to get some real specific teams around that I guess. (Megan, mother of 12-year old boy)

Physicians and dietitians were the HCPs with whom parents had most commonly discussed their child's weight-related issues, but they also saw value in engaging HCPs from other disciplines who they felt could offer support;

A nurse practitioner, or a social worker that would, you know, learn more about [CHILD], and get to know what his interests are, so that you could, you know, tailor something to him, you know? (Lena, mother of a 14 year old boy)

The fundamental issue for parents was having access to professionals who demonstrated an understanding about both weight management and ASD, although that had not generally been something they had experienced.

Connections are important

The need for connections was represented in a range of suggestions from the parents. They firstly highlighted that HCPs needed to make a connection with their child and build rapport with them. This included figures who could act as a role model, making it more likely that their child would follow their suggestions;

For me with specifically with my child, it would be someone who connects with him and encourages him. Someone that he might want to emulate a bit. (Abby, mother of 13-year old boy)

One-to-one support approaches were felt to enable the development of a partnership, but also reflected parental desires for their child in terms of belonging to something;

> *… she really likes one-on-one. She likes having a partner and stuff… I like her to be part of something, because then she's part of the team…* (Alex, mother of 16-year old girl)

While most parents desired a one-on-one approach, some parents suggested alternative ways of accessing support, for example, using technology to facilitate online support from the broader community;

> *Sharing of ideas; I mean, if there was other people out there who have been successful at different approaches. Yeah, I don't think – I mean, I haven't researched to see if there's any kind of a forum for that* (Orly, mother of 17year old boy)

Discussion

The parents in this study provided a detailed narrative of their experiences while seeking support from HCPs for their children with ASD and weight concerns. Parents reported being proactive in seeking weight management supports, which differs somewhat from parental behaviour reported in the literature for typically developing children [39]. Parents of children with ASD (as with other disabilities) must often advocate to get appropriate support in many areas of their child's life [40], and it appears that seeking weight management support is no different. However, even though parents were highly motivated to obtain support and initially encountered a willingness to address their concerns, they ultimately did not get the support they felt their child needed. Even in specialist care, informational support was the primary intervention provided to parents, with the Canada Food Guide mentioned frequently. Of note, the Canada Food Guide was not designed originally as a weight management tool but appears to have been co-opted into standard dietary advice for anyone seeking guidance on weight management. However, informational support alone is highly unlikely to lead to behaviour change [41], especially when the person's circumstances are complex, such as in ASD. Therefore, parents were disappointed to receive this general nutritional information and wanted tailored information. This needed to consider children's restricted food preferences, food preoccupation, challenging eating behaviours and other complicating factors, as well as the additional pressures parents of children with ASD experience on a daily basis.

Aside from specific weight management services, this study reinforced previous reports that children with ASD have limited opportunities to be physically active and often have an unbalanced diet [20]. This is problematic, given that both physical activity and healthy dietary intake confer benefits to children's physical and mental health independent of weight status [42,43]. One parent reported that her child's HCP had focused on becoming more physically active rather than losing weight, an approach that has been recommended by parents of typically developing children [44] and reduces the chance of reinforcing weight stigma [45]. However, HCPs should be cognisant that even messages on physical activity and healthy eating can develop into a pre-occupation for children with ASD with potentially harmful outcomes [11]. However, the disordered eating behaviours parents reported in this study were more typical of ASD, such as sensory challenges and taste aversions. Parents found it frustrating when these characteristics were overlooked or minimized when they sought support for their child. Indeed, previous research has found that healthy weight-related behaviours can be enhanced in children with ASD when HCPs consider the child's challenging behaviours and acknowledge the difficulties parents are facing [20].

The lack of support parents reported likely reflects a lack of HCP training and resources related to ASD, nutrition, and weight management and is likely frustrating for the HCPs as well as the parents. Research has identified many barriers to HCPs discussing weight with typically developing children and their families, including a lack of training, confidence, time, and resources [46,47]. ASD adds an additional layer that makes this even more challenging [48], especially when parents are overwhelmed with managing their child's health and behaviour [11]. Furthermore, previous research has shown that HCPs who prescribe antipsychotic medication to children with ASD to manage upsetting behaviours (e.g., self-harm, violence towards others) experience some moral distress when the medication causes rapid weight gain and they lack the expertise to address it [11]. There is clearly a substantial gap in the healthcare system that prevents parents and children receiving integrated care that includes both disability and weight management expertise.

Strengths and considerations

Although the risks of higher weights in children with ASD have been well documented [16,20,49], this study is the first to explore parental journeys through healthcare services related to their child's weight management and their related support needs. These findings can help advocate for services that combine expertise in both disability and weight management. In addition, the learnings from this study can potentially help mainstream weight management services be more inclusive of children with ASD.

However, while the study sample of nine parents was adequate to start qualitatively exploring the phenomenon of interest [31,50], future research should explore the recommendations provided in this study in more detail with additional parents of children with ASD. Only parents identifying as mothers participated in the study, which reflects the high level of involvement reported by mothers of children with ASD [51]. Further insights could be gained from the important perspectives of fathers and other caregivers. Although the children of parents participating were mostly male, the numbers of females were marginally higher than the typical diagnosis ratio of around 4:1 (males: females) [52]. However, females are being increasingly diagnosed with ASD as their unique profile of symptoms are becoming better understood [53]. The role of gender in seeking and receiving weight management services would provide a more nuanced understanding of this topic.

All participants were recruited from one rehabilitation hospital clinic. Our findings may therefore reflect parental experiences with very similar services. However, parents also reported on experiences with services and HCPs prior to coming to the rehabilitation hospital, therefore providing insights into both community and tertiary services. Furthermore, the lack of individualized care reported in this study was also reported by Polfuss and colleagues in the United States, suggesting that the care provided to parents and children in our study was not limited just to one healthcare context [20]. Taken together, the learnings from this study and those from such previous research can advance healthcare recommendations in a focused manner moving forward.

We did not assess autism severity in the participants' children, although all experienced sufficient behavioural challenges to be prescribed psychotropic medication in a tertiary care setting. While we were therefore unable to explore what supports are needed at different levels of severity, it is likely that these children have the most complex weight-management needs. More research could usefully be conducted with parents of children across a range of autism severity.

An important contextual factor is that all of the children were taking psychotropic medication and therefore, the weight management issues described by parents in this study were largely attributed to medication side-effects. It is possible that the supports required in these circumstances may differ from weight gain caused by other factors. The balance between child behaviour/functioning and weight gain can be complex to navigate and can be distressing for everyone involved [11]. Nevertheless, the increased risk of obesity in children with ASD generally [16] suggests that supports are required even when children with ASD are not taking medication. Furthermore, parents in this study rarely highlighted the role of medication and recommended support strategies that could feasibly be relevant to any child with ASD.

Conclusion

Parents of children with ASD are often proactive in seeking care for their child with ASD when they have weight concerns. Parents reported frustrating experiences navigating the healthcare system for weight management support and experienced a complete lack of individualised care. This study provides a call to action for supports that combine both disability and weight management expertise, to ensure that children with ASD receive integrated and individualised support to maximise their health and wellness.

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Disclosure statement

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