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**Purpose:** To explore parent perspectives of how the attributes of their child's autism spectrum disorder(ASD) impact nutrition, physical activity, screen time behaviors and risk for obesity. Secondarily, we examined the parent's perception of the healthcare providers (HCP) influence on these weight-related behaviors.
**Design and method:** We conducted and audio-recorded telephone interviews with parents of children with ASD (n = 8) using a structured question guide. Data were transcribed and thematic analysis was conducted. Issues surrounding weight-related behaviors and parental strategies used were reported.
**Results:** Two overarching themes with eight subthemes emerged: (1) Challenges related to features of ASD (subthemes included fixation on food, sensory issues/rigidity, developmental factors, impaired social skills, and medication effects) and (2) Challenges related to the care of children with ASD (subthemes included lack of individualized care planning, picking your battles and the impact of ASD on family).
**Conclusion:** Strategies extracted from the parent narratives promoted both healthy and unhealthy weight-related behaviors. The key finding in this study is that some parents did not follow HCP guidance when they perceived that the HCP did not understand their particular situation.
**Practice Implications:** Implementation of healthy weight-related behaviors can be optimized when providers consider the child's challenging ASD behaviors, affirm the difficulties encountered by the family and provide guidance that builds on the individual child/family strengths.
**Key words:** Autism spectrum disorder, Obesity, Pediatric, Qualitative, Nutrition, Physical activity

Children with autism spectrum disorder (ASD) experience persistent pervasive deficits with social–emotional reciprocity, nonverbal communication behaviors and forming developmentally appropriate relationships (American Psychiatric Association, 2013). The estimated prevalence of ASD is 1/68 Americans (Baio, 2014). Co-occurring conditions include cognitive or language impairment, medical or genetic conditions, and other neurodevelopmental or behavior disorders, such as attention deficit hyperactivity disorder (ADHD) (American Psychiatric Association, 2013). In addition, children with ASD are known to have a propensity toward having an abnormal weight status (Xiong et al., 2009). Documentation of overweight and

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obesity prevalence in children with ASD is limited; however, findings support a similar or higher prevalence than the typically functioning population (Broder-Fingert et al., 2014 and Curtin et al., 2014) with reports of obesity as high as 30.4% (Curtin, Anderson, Must, & Bandini, 2010). While not as well documented, there is also a risk for underweight status to occur. In a study by Xiong et al. (2009) of 429 youth (2–11 years) with ASD, 6.8% of the sample were considered underweight.

Specific characteristics of ASD that contribute to obesity risk include impaired sensory responses, food selectivity and intake of high calorie energy-dense foods (Aghaeinejad et al., 2013 and Evans et al., 2012). For example, children receiving applied behavior analysis therapy may receive high calorie food as a positive reinforcement for completing requested behavioral tasks as part of the therapy (Center for Autism Research, 2014). In addition, time spent using computer or video games replaces physical activity and peer socialization (Curtin et al., 2014 and Egan et al., 2013). Furthermore, ASD-related stressors impact parents' ability to implement healthy behaviors, thereby increasing the child's risk of obesity (Curtin et al., 2014).

Literature is limited on the parent's perspective of how the child's diagnosis of ASD impacts the child's weight-related behaviors (nutrition, physical activity and screen time) and risk for obesity. This information is critical for the health care provider's (HCP) understanding of the parent's situation and facilitates individualized care for the family. Accordingly, the purpose of this study was to explore the parent's perspective of how attributes of their child's ASD impact nutrition, physical activity, screen time behaviors and risk for obesity. Secondarily, we examined the parent's perception of the healthcare provider's (HCP) influence on their child's weight-related behaviors.

# Methods

## *Research Design, Sample and Data Collection*

Open-ended, semi-structured telephone interviews with parents of children with ASD were used in this qualitative cross-sectional

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study. Approval was received by the university's institutional review board. Participants were recruited for a concurrent study through the Interactive Autism Network (IAN) Research Database at the Kennedy Krieger Institute, Baltimore. They also provided consent to participate in this qualitative study. The IAN national Web-based registry was clinically validated in the past research (Lee et al., 2010) in which children's diagnosis of ASD was verified by a review of parent- and professional-provided medical records (Daniels et al., 2012). Participants in the present study were eight parents who met the inclusion criteria of having a child between 5 and 16 years of age with a diagnosis of ASD and could read and speak English.

Interviews, facilitated by a structured question guide (Table 1), were approximately 45 minutes long. Open-ended interview questions were focused on the following topics: weight related behaviors (nutrition, physical activity, and screen time), HCP influence on weight management, and parental self-care. In addition to demographic information, parents were asked to report their own and their child's height and weight, in order to calculate body mass index (BMI) as measure of weight status. Participants were also offered the opportunity to add relevant information at the end of the interview.

**Table 1.** Interview guide for autism spectrum disorder and the child's weight-related behaviors: A parents' perspective

First I will ask you some questions about your child's nutrition.

1.) Please tell me about your child's eating habits.
2.) Does your child's diagnosis influence his/her food intake?
    a. If yes, how does their diagnosis influence their food intake?
3.) What does healthy eating mean to you?
4.) Are there any barriers or challenges that make it harder for your child to eat healthy?
    a. If yes, what are these barriers or challenges?
    b. Do you believe these barriers relate to your child's special needs?

Next, I will ask you some questions about your child's participation in activity.

1.) Being physically active is important for many reasons. Tell me about your child's participation in physical activity or other activities.
    a. Tell me about how active your child is in a typical week.
    b. How does your child's participation in physical activity differ on weekdays versus weekends?

   c. Are there any barriers or challenges that make it hard for your child to participate in activity?
      i. If yes, what are the barriers or challenges that make it hard for your child to participate in activity?
   d. Does your child's special needs increase or decrease his/her participation in physical activity and if yes, in what way?

2.) Today screens (such as TV, video players, computers, and phones) play a large role in our children's daily life. Can you tell me about your child's use of screens?
   a. Are there any barriers or challenges that make it hard for your child to limit screen time and if so, what are they?
   b. How does your child's special needs increase or decrease his/her use of screens?
   c. How does your child's special needs increase or decrease his/her general levels of sedentary activity or periods of inactivity?

Now I would like to ask some questions about children being overweight.

1.) Studies have shown that children with special needs have a higher risk of being overweight. What are your thoughts on this?
2.) Are there any barriers or challenges that your child's special needs create when trying to achieve or maintain a healthy weight? If yes, what are they?
3.) How has your child's healthcare provider influenced your ability to manage your child's weight? When answering can you specify if you are discussing your primary care provider or specialty care provider? (can clarify difference of providers if needed)
   a. Reviews your child's weight with you and your child?
   b. Discusses risks of your child being overweight?
   c. Educates about weight issues?
   d. Gives suggestions on how to control weight?
   e. Discusses healthy foods and healthy food choices with you and your child?
   f. Discusses ways for your child to be more active?

My last questions relate to how parents take care of themselves and role model or demonstrate healthy behaviors to their children.

1.) Some parents have mentioned that having a child with special needs can be stressful, which may keep parents from being able to take care of themselves. What are your thoughts on this?
2.) Some parents have said this stress affects their ability to role model healthy behaviors for their children. What are your thoughts on this?

That was my last question. Do you have anything to add that I might have not have asked about? These thoughts can relate to any of the topics we have talked about – nutrition, physical activity, screen time, being overweight or obese, and how parents of kids with special needs take care of themselves. Is there anything else you would like to say?

## *Data Analysis*

The study team was comprised of six members, five nurse researchers/clinicians with backgrounds working with families who have a child with a chronic health condition, obesity and/or ASD and one physical therapy graduate student (F.M.W.) with experience working with ASD. All interviews were conducted by S.H. who underwent training by an experienced qualitative researcher. Interviews were recorded digitally, transcribed verbatim into a word document, and analyzed by the study team individually and subsequently as a group. This iterative process occurred over multiple sessions. Data were subjected to thematic analysis for commonly occurring themes found by examining the participant narratives (Braun & Clarke, 2006). Consideration of the context for the stories helped the team come to an understanding of the influencing factors for the themes (Krippendorf, 2004). Differences in emerging themes were discussed in-depth until consensus was reached. Themes and subthemes were compiled. The study team agreed when saturation was achieved. Relevant and substantive quotations were selected as exemplars. A formula of weight in kilograms divided by meters squared was used to calculate a BMI for parent and child. Weight status (underweight, normal, overweight, obese) was categorized according to the Centers for Disease Control (CDC) adult standards and pediatric age and gender specific graphs (Centers for Disese Control and Prevention (CDC), 2015a and Centers for Disese Control and Prevention (CDC), 2015b).

# Results

## *Participant Description*

All parents who participated in the study were either married or living together (Table 2). Parents were generally well educated with a wide range of income. The majority of the children with ASD were boys (86.5%) and ages ranged from 6–16 years (M = 12, SD = 3.25). In this sample, no children or parents met the criteria for underweight, but 37.5% of children and 25% of parents were considered having a normal weight. The remaining parents (75%) and children (62.5%) were overweight or obese based on the CDC guidelines (Centers for

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Disese Control and Prevention (CDC), 2015a and Centers for Disese Control and Prevention (CDC), 2015b).

**Table 2.** Demographics

| | **N (%)** |
|---|---|
| **Parent** | |
| **Male** | 2 (25) |
| **Female** | 6 (75) |
| **Median age (yrs) (SD)** | 43 (4.03) |
| **Marital status** | |
| **Married** | 7 (87.5) |
| **Living together** | 1 (12.5) |
| **Parent highest degree** | |
| **Attended college** | 1 (12.5) |
| **Completed college** | 2 (25) |
| **Attended post graduate school** | 1 (12.5) |
| **Completed post graduate school** | 4 (50) |
| **Parent annual income ($)** | |
| **30,000–50,000** | 2 (25) |
| **50, 001–75,000** | 2 (25) |
| **75,001–100,000** | 2 (25) |
| **> 100,000** | 2 (25) |
| **Parent weight category*** | |
| **Underweight** | 0 (0) |
| **Normal weight** | 2 (25) |
| **Overweight** | 1 (12.5) |
| **Obese** | 5 (62.5) |
| **Child** | |
| **Male** | 7 (87.5) |
| **Female** | 1 (12.5) |
| **Median age (yrs) (SD)** | 12 (3.25) |
| **Child weight category*** | |
| **Underweight** | 0 (0) |
| **Normal weight** | 3 (37.5) |
| **Overweight** | 1 (12.5) |
| **Obese** | 4 (50) |

*Parent and child weight category based on parent reported height and weight and Centers for Disease Control guidelines.

## *Themes*

Two overarching themes emerged: (1) challenges related to features of ASD and (2) challenges related to the care of children with

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ASD. The first theme had five subthemes, which included fixation on food, sensory issues/rigidity, developmental factors, impaired social skills, and medication effects. Sensory issues and rigidity were combined into one subgroup based on the exemplars provided by the parents. Three subthemes were identified for the second theme: lack of individualized care planning, choosing your battles and impact of ASD on family. See Table 3 for a summary of themes, subthemes and strategies used by parents of children with ASD.

1. Challenges Related to Features of ASD

   This theme captured two types of responses in the 5 sub themes. In most of the sub-themes parents reported both difficulties or issues encountered and the strategies used to respond to the difficulties.

   **Fixation on food.** *Fixation on food* was defined as the child's excessive hunger or an increased focus on food. Six of eight parents reported that their child had a higher than expected appetite. Four of eight parents conveyed that this increased appetite resulted in the child eating constantly, "I guarantee you if we did not supervise everything he put into his mouth to some degree, he would probably gain 20 pounds in a month because he will just eat constantly." One parent managed their child's increased focus on food by creating menu boards, "We plan the meals in advance…and we have a menu board on the kitchen wall so he knows what dinner will be."

   Parents managed their child's increased appetite through a variety of strategies, such as having the child ask before obtaining food. "He does have to ask… 'cause otherwise he will snack all day….he is an eating machine and he will most inevitably pick whatever foods are not good for him." Another parent used a sign in the kitchen to let the child know when he could get food, "We…have a little magnetic sign that shows if the kitchen is open or closed…" Another example involved physically locking cupboards and refrigerator to control food intake, "She asks us to do that for her [get snacks] because we have everything locked up. Same with the refrigerator. We have it locked so she can't get in."

   Two of the eight parents reported that they thought their child's fixation on food was due to boredom or wanting more attention from the family, "When we do not keep his mind very active…

he reinterprets it as hungry. If we did not keep him constantly figuring out something else to do… he would eat all day long." or "If we're not directly playing with her or keeping her at bay in some way, her default is to go play with food, eat the food…so I think what we're seeing is not so much that she's hungry all the time, but that she's just bored."

**Sensory issues/rigidity.***Sensory issues* were defined as unusual physical or emotional responses to taste, odor or textures. Parents described these responses as leading to picky eating or having a limited interest in food selection. The rigidity component is related to the need for routine. Seven of the eight parents stated their child had picky eating, "He's…extremely picky. I don't know if it was a sensory issue, a color issue, because it was like no rhyme or reason to what he would eat or wouldn't eat…" sensory issues such as smell, taste or appearance of foods, "A lot of the good healthy stuff, may have strong odors or kind of funky texture and he just doesn't want it" and rigid eating patterns that resulted in the child eating similar foods each day, "…every morning he has to have his cereal and a yogurt…. And for lunch…. a peanut butter and jelly sandwich, it has to be the same all the time", a preference for processed or energy-dense foods, "I think a lot of it… is that the foods they tend to fixate on are processed…almost every kid I know that has autism…. has a thing with chicken nuggets" and a decreased acceptance of fruits and vegetables, "I think she doesn't enjoy fruits and vegetables as much. I mean, she's tasted them, but she wouldn't, she doesn't go back to them. They're not as good as chips and certain candies that she would go back to."

Parents dealt with picky eating by including the child in food choice decision-making; however, offered limited preapproved or "healthier" options, "I do give him some input, but I…limit the choices that he's got with that input." Another family limited the amount of junk food in the house, "I'll give him the junk food, but I don't keep a lot of it around for him." Other parents made recommendations based on their experiences, "I guess the biggest thing is, is the earlier that somebody can find a happy balance …I'm glad that my husband and I started at a very early time developing this pattern of everything for him… the only thing I wish I would have done was push a little harder on the foods earlier, but at the time it was not a battle I was ready to partake in…." When parents did attempt to introduce new foods they admitted it was not easy, "There are still days that he kind

of gives me more grief about it, but he's eating a lot more food." Other parents talked about rewarding or bribing with food, "He does like Pizza Hut pan pizza…if he asks for a pizza, you got it, usually as a reward for something." or "We've also done a lot of…bribing, like you can have a little dessert if you try this type of thing…..in the past six months he has adapted to many new foods."

**Developmental Factors.***Developmental factors* were defined as the lack of age-appropriate developmental skills parents attributed to ASD including poor coordination, inability to handle frustration, and decreased reaction time. Parents talked about these factors as reasons for the child's lack of ability or interest in physical activity. "We haven't had a whole lot of luck with him with team sports. His coordination isn't great and his attention isn't the greatest and his reaction time is slower than the other kids." or "…he tries really hard to do stuff and then he gets frustrated because, like riding a bike, he wants very badly to ride a bike, but after just a couple short tries he gives up."

**Impaired social skills.***Impaired social skills* was defined as a deceased ability to communicate with others in a social setting. All eight parents reported their children participated in a decreased amount of physical activity on a regular basis compared to the typically developing child and they attributed this to their child having limited or impaired social skills related to ASD, "I think because of his autism and because he doesn't know how to communicate very well or talk to other people that that does affect him having the desire to… join a sport or be around other people and participate in activities." Another mother expanded on this concern: "I don't know…that he doesn't want to participate in a team or on a team, but I think he just doesn't understand…what makes a team work."

Children that did participate in physical activity preferred independent activities such as swimming, karate or free play. "If it's an individual thing like hiking or biking or skiing, he loves to ski, then you know, he'll quite happily do that for, for hours…if it's not "exercise he's all over it if it's something he enjoys doing." Another family verbalized how they participated in physical activity as a family, however limited the activities to small increments of time, "We do have a… pool outside our house that we all get in and play in throughout the summer. We do have a couple of rope swings…. that we'll take the kids down and push them…and we have a really long driveway that …we'll

all walk out there, close the gate and walk back down together. So we just try to find little things where they might be 10 or 15 minutes."

Parents attributed the increased interest and time spent on sedentary activities, such as watching television, playing video games, iPad or computer use, to the child's impaired social skills. Seven of the eight parents indicated that their child participated in an increased amount of screen time compared to what they thought was recommended for children. "He is very much an inside kid. He likes anything with a screen. When he goes outside, he'll more likely go outside with one of his devices."

Parents rationalized increased screen use by their child as beneficial, as screens, provided an opportunity for the child to learn social behaviors and improve communication skills. Parents were conflicted about limiting screen time due to the perceived value and enjoyment for the child. "It's hard to limit (screen time), not only because he happens to be really good at video games and it's something that he enjoys and makes him happy, but also when he was very little and first diagnosed and was basically non-verbal and didn't have a lot of social skills… it was videos that made him progress."

Acknowledging the child's preoccupation with screens, parents often used screen time as a reward to engage the child in a chosen behavior, "Yesterday I did notice that he did want to go outside …because there was the carrot thing of…you guys can watch TV or a movie or something if you guys play outside for about an hour." or "My goal for school is that screen time will have to be earned (through good behavior)."

**Medication effects.***Medication effects* were defined as the side effects parents attributed to prescribed medications that are used to manage their child's comorbid conditions. A subset of four of the eight families perceived the child's medication, primarily for ADHD in this study, impacted the child's intake of food by decreasing the appetite when the medication was active, "Now he's been diagnosed with ADHD, so he's actually on medication that he's not really hungry during the day. So breakfast we try to feed, feed, feed…before the medicine kicks in. And then….at night for dinner, we try to feed, feed, feed…" In these instances, parents expressed increased concern with the child not eating enough, so they attempted to get extra

calories into the child, usually through a high-fat or high-calorie options, "We try to give him a lot of protein and a lot of fat foods… like, tortilla chips with cheese melted on top. We'll melt cheese and pepperoni on a plate…. He loves mac and cheese, but only the kind - the microwave kind that…is already premixed."

2. Challenges related to the care of children with ASD

This theme captured the difficulties parents encountered with the healthcare system and within their own families when caring for their child with ASD and the strategies they used to respond to these difficulties.

**Lack of individualized care planning.***Lack of individualized care planning* was defined as the parents' perception that the HCP did not take their particular situation or the unique behaviors of the child into account when providing guidance related to nutrition, activity and related recommendations. One parent reported that the HCP did not discuss specific weight-related behaviors such as activity or nutrition; the remaining seven parents acknowledged receiving basic or general recommendations on weight-related behaviors. Parents perceived that the HCP did not tailor weight-related assessments and interventions to their child's needs or provide the needed information on how to follow through with recommendations. "The only thing that we've discussed specifically… is the fact that he does watch more TV, etc., than we would like and they say, "Try to limit it," but that's kind of easier said than done." Another parent discussed, "A lot of suggestions were basically cutting his portions down…and getting him (into) some kind of like a sport… So I'm trying to work out …what kind of a sport because he doesn't like to be touched or anything like that, so obviously football or something is out of the question."

**Choosing your battles.** 'Choosing your battles' refers to choosing when to address a situation or when to let it go and accept the consequences. The consequence of not addressing the situation may be weight gain. But the parent's chooses to avoid the meltdown that would surely have occurred had the parent chosen to confront a behavior or substitute an unfamiliar food and disrupted the child's routine. Parents choose when and if to address a situation based on a multitude of factors including how well the day has gone, what the competing

priorities are, or how much energy the parent has to address the situation at that particular time. Parents reported that they heard HCP suggestions related to weight-related behaviors, but reported to not always following through on recommendations, "Nutrition has come up… I mentioned that I give him whole milk, and they said, "Well, if you could make it 2% that would be better." I just couldn't quite bring myself to bring it down.... the next year, they said, "So you still have him on the whole milk?" And…he's a teenager by then. So I said, "Yes....I almost didn't want him (her son) to hear that the doctor was recommending 2% ….because of that whole rules regimented thing. I didn't want him to feel, like, he's breaking a rule by having whole. He's still used to whole and it's just my choice to give him whole." or "I think they did mention something about a limit on TV, I think. Oh, screen time… I can't remember the limit, but he said it to me, and I said, "Oh, okay." Parents also confided that they made certain decisions based on avoiding negative behaviors or meltdowns, "Yes, because if I am trying to get him to get off of it (screens)… then we start having a meltdown and…sometimes it gets so bad it's just like I don't even want to deal with it. Sometimes he may get so upset that you kind of just stop yourself and go, well let's just leave him alone then."

All eight parents seemed knowledgeable of what constitutes a healthy diet. Parent consensus was that HCP did not provide any new information to enhance management of their child's weight status, "For me, it's just a balanced meal, not too much of any one food group, like a small amount of protein, low carbs, a nice vegetable and fruit, lots of water." but also shared barriers that prohibited them from achieving a healthy diet, "…we don't always shop healthy. Sometimes we buy what's convenient and not necessarily what's healthy."

**Impact of ASD on family.** The impact of ASD on family encompassed issues that parents believed that influenced their ability to manage the individual and collective needs of the family. These issues included parental fatigue, frustration and lack of time. Parents reported that increased time constraints prohibited them from providing healthier food options or spending time together. Two examples include, "We spend so much time handling him that we don't get as much time to prepare healthy meals or sit down and eat." and "…for the most part, we don't really go out a whole lot together. We'll go out separately."

Parents recognized that having a child with ASD created stressors within their daily life and relationship with their significant other. "You have a shorter fuse. You have less patience. You're tired. Both my husband and I work full-time and then come home and have to deal with a lot. ….sometimes I just want to sit on the couch…and just do nothing." Another parent talked about splitting responsibilities as an approach to balance caring for the child and managing the household, "We'll tag-team…".

Two of the parents talked about the importance of caring for self and for the relationship with their significant other. Two responses include, "We have always had a very specific quiet time and bedtime for him so that we had at least an hour or two in the evening to wind down so we can keep our psychological selves more in check…." and "I really feel like you have to take care of yourself in order to be able to take care of them. …I've always…had this hierarchy of….their needs come before my needs, but my needs come before their wants. So as long as I can figure out…what they need, what they want, and make sure I'm taking care of myself, I think we keep a pretty good balance going."

Table 3.

Study themes, subthemes, issues and strategies identified by parents of children with autism spectrum disorder

| Themes and subthemes | Issues | Parent strategies |
|---|---|---|
| 1. Challenges related to features of autism spectrum disorder | | |
| **1a. Fixation on food** | Increased appetite. | Used menu boards to alleviate child's focus on what food would be served. |
| | | Had child ask parent before taking food. |
| | | Used open or closed sign on kitchen door. |
| | | Physically locked cupboards and refrigerator. |
| | | Tried to keep the child busy so they did not focus on food out of boredom. |
| **1b. Sensory issues/rigidity** | Picky eating with a preference for processed or energy-dense foods. | Provided same foods daily, but chose healthier food options. |
| | | Included child in decision making, but offered limited preapproved "healthier" options. |

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| Themes and subthemes | Issues | Parent strategies |
|---|---|---|
| | | Allowed junk food, but limited the amount of it in the house. |
| | | Introduced new behaviors early in life. |
| | | Consistently introduced new foods. |
| | | Provided unhealthy food as a reward or bribing with food. |
| **1c. Developmental factors**<br>**1d. Impaired social skills** | Decreased physical activity. | Increased opportunities for individual activities, i.e. swimming, karate, free play, hiking, skiing, etc. |
| | Decreased team sports. | Participated in physical activity as a family. |
| | Increased sedentary activity with specific interest in screen time (i.e. television, video games, iPad, or computer use). | Limited activity to small time increments. |
| | | Did not limit screen time due to seeing it as beneficial and enjoyable to the child or as a mechanism for communicating with others. |
| | Decreased outdoor time. | Allowed screen time to avoid meltdowns. |
| | | Allowed screen time as a reward. |
| | | Allowed screens to be used outdoors. |
| **1e. Medication effect** | Comorbid conditions resulted in the use of medications with side effects of affecting appetite, i.e. decreased appetite secondary medication for attention deficit hyperactivity disorder. | To counteract decreased appetite brought on by medication, family increased food offerings before medication in the morning and at night after medication wore off.<br>Increased consumption of extra calories through high-fat or high-calorie options, i.e. macaroni and cheese, tortilla chips with melted cheese, pepperoni and melted cheese. |
| 2. Challenges related to care of the child with autism spectrum disorder | | |
| **2a. Lack of individualized care planning** | When communicating with the child's health care provider, parents perceived that the provider did not individualize care for autism spectrum disorder when discussing weight-related behaviors. | Attempted to figure out options on their own to enact the behavior change. |
| **2b. Picking your battles** | Parents chose when to address a situation or when to let it go and accept the consequences. | Verbally agreed with the health care provider, but did not follow through when it did not seem feasible.<br>Allowed their child to participate or perform activities that are not recommended in |

| Themes and subthemes | Issues | Parent strategies |
|---|---|---|
| | | order to avoid a meltdown.<br>Purchased food based on convenience versus health value. |
| **2c. Impact of autism spectrum disorder on family** | The challenges associated with autism spectrum disorder impacted the family's ability to meet the needs of the family members' secondary parental fatigue, frustration and lack of time. | Enacted a specific bedtime for child that allowed time for parents to be together.<br>Attempted to balance needs of the child versus wants and cared for themselves.<br>Did not prepare healthier food options.<br>Did not spend time as a family.<br>Parents did things separately or tag teamed care of the family.<br>Parents did not participate in outside or social activities. |

# Discussion

In this study, eight parents offered insight about their experiences with their child's weight-related behaviors, including nutrition, physical activity and screen time and the potential risk for obesity. They also described HCP influence on these weight-related behaviors. These experiences underscore the increased obesity risk in children with ASD. Individual characteristics of ASD, responses by the family and the environment that the child lives in appears to have the ability to impact the child's risk for obesity.

Many parents are overwhelmed and make consequent choices based on convenience or to prevent triggering challenging behaviors in their child. As unhealthy cycles begin to emerge, children develop new patterns that are difficult to change. When discussing weight-related behaviors with their HCPs, few HCP offered recommendations appropriate for a child with ASD. The one-size-fits-all recommendations were either inappropriate, short-lived or disregarded by parents. Healthcare providers must be supportive of parent concerns and collaborate in the development of appropriate and reasonable strategies to manage the child's weight-related behaviors.

One of the weight-related concerns parents discussed was related to obtaining a balanced nutritional intake for their child. Most of the children had a large appetite and subsequent large food intake

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which parents associated with risk of weight gain. Parents noted that eating out of boredom contributed to this eating pattern. The parent's perception of increased food intake influencing weight was supported in the literature (Barlow and Expert Committee, 2007 and Evans et al., 2012) with the example that an excess intake of only 50 kcal/day can result in a 5-lb./year weight gain (Strasburger, 2011).

Comorbid ADHD and eating in the absence of hunger have been implicated as risk factors for obesity (Khalife et al., 2014 and Perez-Morales et al., 2014). Some parents attributed their child's decreased appetite to medications used to manage ADHD and compensated by aggressively increasing calories and incorporating high-fat, energy-dense foods. In the long-term, this cycle is not helpful as it contributes to "disordered self-regulation of eating" and unhealthy eating patterns (Rauber, Campagnolo, Hoffman, & Vitolo, 2015).

Parental concerns related to the effect of their child's sensory issues on food preference and the associated adherence to specific food routines was also supported in the literature (Curtin et al., 2014 and Kral et al., 2013). Parents struggle with their child's picky eating, such as preference for simple carbohydrates and resistance to fruits and vegetables. A small subset of parents were able to increase the food options their child choose through diligent attempts at introducing new foods. Increased appetite and attempts to limit the child's food intake were described as daily battles. Restriction of food is seen counterproductive and is associated with a higher child BMI (Jansen et al., 2012 and Scaglioni et al., 2011).

Use of energy-dense foods as rewards is another concerning practice that contributes to a child's preference for unhealthy food choices. While some parents mentioned the use of ABA therapy, they did not specify if their choice to reward the child with food was based on what was learned in therapy or done on their own accord. When used within ABA, desired behaviors are positively reinforced with a "small" reward (Weitlauf et al., 2014) such as high fives or small pieces of a favorite food (Center for Autism Research, 2014). Within this study, food rewards were often larger options. Literature on obesity prevention in the general population has discouraged rewarding with food due to an association with negative outcomes, such as binge eating and increasing preference for unhealthy foods

(Puhl & Schwartz, 2003). The use of food rewards in this sample could be perpetuating the child's already engrained preference for energy-dense foods and limited diversity in food selections. Further work is needed on the use of food as a reward in children with ASD.

Parents also discussed certain characteristics in their child that hindered participation in team sports and many physical activities, specifically, lack of coordination and impaired social skills. Daily participation in moderate to vigorous physical activity is recommended for achieving a healthy weight (Barlow & Expert Committee, 2007). In the typically developing population, sports and team activities are often used to increase physical activity. On the positive side, parents noted that their child was more likely to perform physical activities if they were of an independent nature and something they enjoyed. In addition to enrolling their children in chosen activities, such as karate or swimming, parents would also engage in activities with their child in smaller blocks of time.

Screen time was a commonly described favorite activity. While regular participation in physical activity is advised, it is recommended that time spent in sedentary activity, including "screen time" be limited. Increased screen time has been implicated as a risk factor for childhood obesity by taking time away from physical activity, increasing snacking and the exposure to unhealthy foods in advertisements (Strasburger, 2011). The present study highlighted the complexity associated with limiting screen time within the ASD context. Findings substantiated that in addition to entertainment, children used screens as a mechanism for social learning and communication (Egan et al., 2013). Parents in the present study expressed concerns about limiting something they saw as beneficial and enjoyable for their child. It did not appear that parents placed strict limits on screen time and often used screen time as currency for good behavior.

Health care providers are able to impact childhood obesity by monitoring weight trends, health behaviors and providing anticipatory guidance to promote these behaviors. Providers experience difficulty delivering the needed guidance to families due to time limitations, fear of offending, or due to use of an authoritarian approaches (e.g. "do this" versus tailoring their recommendations) (Plourde, 2012 and Vine

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et al., 2013). The risk of obesity adds to the complexity of ASD, creating additional challenges for provider attempts to provide individualized care. In the present study, one HCP advised the family that the child needed more physical activity and encouraged enrollment in a sport; the HCP neither considered the child's challenges nor assessed the child's ability. This lack of assessment and use of generalized advice left parents struggling for direction. Generalizations cannot be made for children with ASD. The findings in this study suggest that HCPs need to conduct a targeted assessment of the individual child's strengths (i.e. prefer independent activity, follows rules or routines, etc.) and challenges (does not like to be touched), and assist the family in generating a reality-based plan to increase physical activity. In developing plans of care with parents, HCP must ascertain family priorities and parental stressors. In this study, parents chose to weigh the risk/benefit ratio of a situation. The decision to follow through with recommendations was based on the associated consequences of that decision. In addition, if the specific recommendations were not a priority for the family, the likelihood of following through was limited.

Negative effects of time and fatigue on family functioning have been documented in previous studies (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Families perceived that stressors associated with caring for their child with ASD hindered their ability care for themselves and prepare healthy foods. Positive parenting techniques were discussed including early initiation of behavior change, providing opportunities for the child to choose between acceptable options, limiting the amount of unhealthy choices kept in the house and trying to participate in physical activities with the child. Alternatively, parents' difficulty with consistently setting limits compromised achievement of desired behaviors. A subset of parents shared how they created time for themselves, although time spent together as a couple was limited. Parents reported their belief that time spent pursuing their own interests would ultimately contribute to better parenting.

This study provided useful insights for HCPs about parent behaviors. Parents appeared knowledgeable about nutrition and physical activity recommendations; however, having this knowledge did not necessarily translate to enactment of associated behaviors.

This finding was attributed to the risk/benefit ratio of the situation, with emphasis on what occurs in the moment versus the future. While a parent may know the recommendations for nutritional intake, if the immediate benefit of avoiding a meltdown is compared to the potential later risk of gaining weight, the parent may choose to allow the unhealthy food. Continued reoccurrence of this reaction solidifies unhealthy behaviors. Understanding these family challenges can assist the HCP in working with families to develop alternative strategies.

The study has limitations. Interviews were conducted via telephone versus face-to face, thereby limiting interpretation to verbal responses. Six of the eight interviewees were mothers and seven of eight of the children were males, thereby limiting perspectives of fathers and parenting females with ASD. While a sample size of eight interviews could be seen as a limitation, saturation was achieved. It is possible that a larger or more diverse sample might have generated additional critical information. No children were identified in this study as being underweight. Inclusion of the experiences of parents of underweight children may have offered additional insights. Future studies are needed to assess the acceptability and feasibility of interventions focused on obesity prevention and management for children with ASD. These interventions need to be individualized and aimed at improving family management of challenging behaviors, increase family functioning and developing strategies that optimize healthy eating choices and physical activity. Acknowledging that underweight status can also occur, future qualitative studies could address the parents' concern for all weight abnormalities.

## Conclusion

This study highlights weight-related behaviors and strategies used by parents of children with ASD. Although these children have many of the same weight-related behaviors as typically developing children, the situation is exacerbated by the unique and challenging characteristics of ASD. These challenges can lead to parents making choices that may potentially reinforce negative health behaviors. Awareness of these ASD associated challenges and building on the child's strengths can decrease the incidence of challenging, food-

related behaviors and increase viable options for improving weight management in this vulnerable population.

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