



## The Influence of a Developmental Disability on the Child's Weight-Related Behaviors: A Parent's Perspective

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### ABSTRACT

**Purpose:** To examine the parent's perspective on how the child's diagnosis of a developmental disability, the weight-management support of the healthcare provider and parental self-care and role modeling influenced the child's weight-related behavior, (i.e. nutrition, physical and sedentary activity).

**Design and methods:** This qualitative study, guided by Bronfenbrenner's Ecological System's Theory, used a one-on-one semi-structured telephone interview conducted with 15 parents of children 5–16 years of age with spina bifida or Down syndrome. Interviews were professionally transcribed and thematically analyzed. In addition, parents reported height and weight for themselves and their child.

**Results:** Three overarching themes within the context of how the child's diagnosis influenced the child's weight-related behaviors emerged: 1) Developmental Characteristics or Condition-Related Factors captured qualities of the child's condition and interactions with the healthcare system; 2) Social Consequences encompassed the influence of the diagnosis on relationships of the child and family members; and 3) Parenting Influences and Practices captured three types of responses including parent perceptions of the diagnosis, parenting behaviors, and parental self-care behaviors, each influencing the child's weight-related behaviors.

**Conclusions:** Parents illuminated the social and medical challenges that the family encountered due to the child's diagnosis. These challenges directly and indirectly influenced the child's physical and sedentary activity and nutritional intake. Although challenges were present, the strength and determined attitudes of the families became apparent.

**Practice implications:** The promotion of self-care and examination and validation of the emotional aspects of parenting a child with a disability may positively influence the child's weight-related behaviors.

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### Introduction

Youth with disabilities are 35% more likely to be obese than their typically developing (TD) peers (Bandini et al., 2015). Although this statistic is staggering, there is limited literature focused on weight-related behaviors of children with a developmental disability. The potential consequences of childhood obesity are diverse, including a negative impact on the youth's physical, social, and emotional well-being (Gungor, 2014; Reilly & Kelly, 2010; Sahoo et al., 2015). In youth with developmental disabilities, obesity may contribute to the development of secondary comorbidities or the exacerbation of underlying conditions associated with the disability, such as mobility impairment,

deconditioning, pain, and social isolation (Rimmer, Rowland, & Yamaki, 2007). These concerns can inhibit the individual's ability to transition to independence and further challenge the ability of the caregiver to provide assistance (Fox, Witten, & Lullo, 2014; Reinehr, Dobe, Winkel, Schaefer, & Hoffmann, 2010; Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010; Wong, Dwyer, & Holland, 2014). As the risk for obesity is increased in children with disabilities, it is imperative to examine how the child's diagnosis and weight are interrelated.

Children with disabilities often require care or family involvement that may continue into adolescence and adulthood (Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012). The amount of family involvement or care needed will vary depending on the child and diagnosis. The additional responsibilities and potential stressors associated with caring for a child with a disability may negatively affect the caregiver's ability to provide self-care (Redquest, Reinders, Bryden, Schneider, &

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Fletcher, 2015) which can have a secondary impact on the child. In a study of mothers of children with developmental disabilities, participants acknowledged that they often ignored their own health needs in order to care for their child; however, participants also recognized that they needed to care for themselves in order to optimally care for their families (Khanlou, Mustafa, Vazquez, Davidson, & Yoshida, 2017). In children with complex health needs, the time spent by the parent addressing the additional needs of the child decreases the time that the parent spends in social activities or providing self-care (McCann, Bull, & Winzenberg, 2012). In a study of 263 parents of children diagnosed with cancer, parents reported negative implications on their own health including poor nutritional intake and decreased participation in physical activity and social activities (Wiener et al., 2016). Parents' inability to perform self-care and participate in their own health promotion can have negative implications on the child's behavior and health habits. This occurs mainly through the parents' inability to role model and spend time supporting healthy behaviors in their child.

Obesity is complex, with a multifactorial etiology that includes biological, psychosocial and environmental components (Must et al., 2014). While not isolated, the primary factors identified with obesity typically focus on nutritional intake, physical activity, and sedentary activity. These weight-related behaviors are influenced by internal and external factors that vary throughout the lifespan (Campbell, 2016). Early in life, children are largely dependent on parents and caregivers to provide their dietary options and their opportunities to be physically active. As the child ages their schools, neighborhoods, communities, and peers become prominent influences upon diet and activity options (Must et al., 2014). During this progression, individual habits are formed which further solidify the child's weight-related behaviors specific to nutritional intake and participation in physical and sedentary activity (Birch, Savage, & Ventura, 2007; Campbell, 2016; Goldfield, Harvey, Grattan, & Adamo, 2012). As the child's independence increases, the role of the family may evolve but continues to be pivotal, with the family's innate day-to-day actions either supporting or challenging the child's emerging weight-related behaviors. The influence of the family on a child's weight-related behaviors can be both direct and indirect through role modeling and the family's attitudes surrounding these behaviors (Campbell, 2016; Campbell et al., 2007; Savage, Fisher, & Birch, 2007).

With increased involvement in the child's daily life, caregivers of children with disabilities may have a unique awareness of the child's weight-related behaviors. The aim of this study was to examine the parent's perspective on how the child's diagnosis of a developmental disability, the weight-management support of the healthcare provider and parental self-care and role modeling influenced the child's weight-related behaviors (i.e., nutrition, physical and sedentary activity). The overall qualitative study included parents of children with Down syndrome, spina bifida and Autism Spectrum Disorder. These three diagnoses were chosen as they each have a higher prevalence of obesity as compared to their typically developing peers. While the goal of the overall study was to articulate the diagnoses' influence on the child's weight-related behaviors from parents of children with a developmental disability, the attributes of Autism Spectrum Disorder and the data related to the parents of children with Autism Spectrum Disorder had especially distinctive perspectives. Thus, those parents' data were reviewed, analyzed, disseminated and published separately by a core group of authors with expertise related to Autism Spectrum Disorder (Polfuss et al., 2016). This study focused on parents of children with Down syndrome and spina bifida to exemplify a cognitive and a physical disability. This study was guided by Bronfenbrenner's Ecological System's Theory (EST), which is often adapted to represent the interactive contextual perspective of childhood obesity (Fig. 1). This theory highlights that the child is embedded by multiple contexts that expand from direct to broad social contexts (Bronfenbrenner, 1986; Davison & Birch, 2001). With childhood obesity, the child's weight is influenced

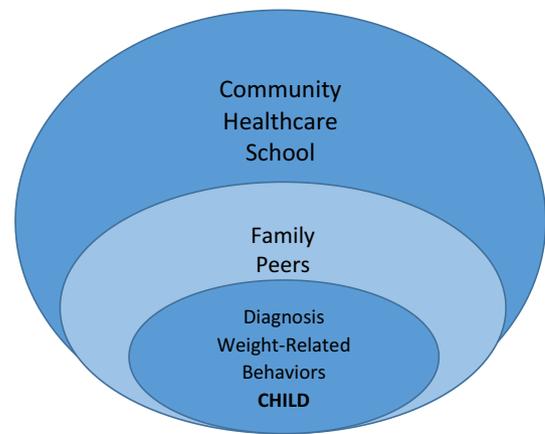


Fig. 1. Childhood obesity within ecological systems theory.

by surrounding environmental contexts and ongoing interactions between multiple systems. For the purpose of this study, the child's diagnosis and daily weight-related behaviors of nutrition and physical and sedentary activity are in the microsystem. The mesosystem includes family and peers. The exosystem includes community, healthcare, and school (Fig. 1). Application of the EST recognizes the contribution of the individual's inherent traits, daily activities (including weight-related behaviors), role of family and peers and the surrounding environment to their weight status (Polfuss & Frenn, 2012).

## Methods

### Research design, sample and data collection

This qualitative research study included one-on-one semi-structured telephone interview with each participant, averaging 45 min in length. A single interviewer conducted the interviews and followed a semi-structured interview guide, previously published, that included open-ended questions (Polfuss et al., 2016), demographic questions, and the parent's self-report of the height and weight of the parent and their child. Interview questions focused on how the child's diagnosis, the healthcare provider's weight-management guidance, and the parents self-care and role modeling of health behaviors influenced the child's weight-related behaviors of nutrition and activity (physical and sedentary). Institutional review board (IRB) approval was obtained through the university prior to the initiation of the study. The IRB approved study advertisement was placed at the end of a national quantitative online study that recruited participants from two national organizations, DS Connect™: The National Institutes of Health National Down Syndrome Registry and the Spina Bifida Association. If interested, participants contacted the principal investigator and a phone interview was arranged. A consent form was provided online and reviewed by the interviewer. Participation in the interview indicated voluntary consent and waiver of documentation of consent was granted by the IRB. The purposive sample consisted of 15 English-speaking parents who self-identified as having a child between 5 and 16 years of age diagnosed with either Down syndrome or spina bifida.

### Data analysis

The qualitative body of data in this study was acquired from the telephone interviews, which were digitally recorded and professionally transcribed verbatim. The three-member study team (MP, CK and CD) individually reviewed the de-identified transcripts and generated initial themes and subthemes based on recurring topics within the interviews pertaining to factors influencing weight-related behaviors among children with developmental disabilities. The team then met as a group to

discuss their individual findings and perceptions of the meaning derived from the interviews and potential biases in each researcher's interpretation. This process was repeated multiple times, resulting in rigorously selected themes, which were continuously compared to the transcripts and revised until there was a consensus that the themes provided an accurate and clinically meaningful representation of the data (Braun and Clarke, 2006). Meeting notes and iterations of the process were maintained. To address credibility and rigor of the analysis, a fourth author (KS), with content expertise and authorship from the previously published results related to Autism Spectrum Disorder was included. This author (KS) reviewed the emergent themes, questioned and confirmed the fit of the themes and verified the integrity of the process between the two separate analyses (Autism Spectrum Disorder and combined spina bifida and Down syndrome).

Quotes from the interviews were chosen that best represented the emergent themes. The reported heights and weights for the parents and children were used to calculate a Body Mass Index (BMI) based on the formula of kilograms divided by height in meters squared ( $\text{kg}/\text{m}^2$ ) for the participants. The BMI was used to categorize the parent and child's weight status according to the definitions provided by the Centers for Disease Control (CDC) for adults and children based on age and gender (Centers for Disease Control and Prevention, 2018).

## Results

### Participant characteristics

The sample included seven parents of children diagnosed with spina bifida and eight parents of children diagnosed with Down syndrome. The majority of the caregivers interviewed attended or completed a college degree (93%). Familial income was skewed to a higher annual income, with two thirds (67%) of the participating parents reporting annual income levels that exceeded \$75,000. The gender of the participating parents was primarily female (87%) and more evenly split for the children with 60% being male. The majority of the children and participating parents were considered overweight or obese (60% and 80% respectively). The overweight and obesity status of the children was higher for the children diagnosed with spina bifida (57%) as compared to the children diagnosed with Down syndrome (50%). The overweight and obesity status for the parents was more similar between diagnoses, but the parents of children diagnosed with Down syndrome who met the criteria for overweight or obese was higher when compared to the parents of children with spina bifida (88% and 72% respectively) (Table 1). When examining the concordance of weight category between parent and child, of the 12 parents who identified as overweight or obese, six of those children also met the criteria of being overweight or obese, five children were of normal weight, and one child was underweight. Conversely, of the remaining three parents who were of normal weight, two children were overweight or obese and one matched the parent as being of normal weight.

#### Themes.

Three overarching themes with four subthemes captured parents' perceptions of how their child's diagnosis influenced weight-related behaviors: 1) Developmental Characteristics or Condition Related Factors, 2) Social Consequences, and 3) Parenting Influences and Practices (Table 2).

### Developmental characteristics or condition-related factors

This theme captured the qualities of the child's condition, interactions with the healthcare system, and the parent's responses to these factors within the context of weight-related behaviors. Physical and cognitive traits and healthcare interactions emerged as subthemes.

**Table 1**  
Demographics.

	Spina Bifida N = 7	Down syndrome N = 8	Total N = 15
Parent			
Male	1 (14.3%)	1 (12.5%)	2 (13.3%)
Female	6 (85.7%)	7 (87.4%)	13 (86.7%)
Mean age (yrs) (SD)	37.9 (6.1)	42.9 (7.7)	40.53 (7.2)
Marital status			
Married	6 (85.7%)	7 (87.5%)	13 (86.7%)
Single, divorced	1 (14.3%)		1 (6.7%)
Parent highest degree			
Completed high school	1 (14.3%)	0	1 (6.7%)
Attended college	1 (14.3%)	1 (12.5%)	2 (13.3%)
Completed college	3 (42.9%)	4 (50%)	7 (46.7%)
Attended post graduate school	0	1 (12.5%)	1 (6.7%)
Completed post graduate school	2 (28.6%)	2 (25%)	4 (26.7%)
Parent annual income (\$)			
<30,000	1 (14.3%)	1 (12.5%)	2 (13.3%)
30,000–50,000	1 (14.3%)	1 (12.5%)	2 (13.3%)
50,001–75,000	1 (14.3%)	0	1 (6.7%)
75,001–100,000	1 (14.3%)	3 (37.5%)	4 (26.7%)
>100,000	3 (42.9%)	3 (37.5%)	6 (40%)
Parent weight category			
Underweight	0	0	0
Normal weight	2 (28.6%)	1 (12.5%)	3 (20%)
Overweight	2 (28.6%)	2 (25%)	4 (26.7%)
Obese	3 (42.9%)	5 (62.5%)	8 (53.3%)
Child			
Male	3 (42.9%)	6 (75%)	9 (60%)
Female	4 (57.1%)	2 (25%)	6 (40%)
Median age (yrs) (SD)	9.1 (3.3)	9.5 (3.2)	9.3 (3.1)
Child weight category			
Underweight	1 (14.3%)	0	1 (6.7%)
Normal weight	2 (28.6%)	4 (50%)	6 (40%)
Overweight	2 (28.6%)	1 (12.5%)	3 (20%)
Obese	2 (28.6%)	3 (37.5%)	5 (33.3%)

### Physical and cognitive traits

Physical and cognitive impairments were defined as the characteristics associated with the child's disorder, and discussion of how these characteristics influenced the child's weight, particularly in the cases of physical activity and nutrition.

**Mobility, gross motor, muscle tone.** The child's muscle tone, endurance and mobility were consistently reported to influence the child's capacity to engage in physical activity. According to one parent, "I think that the hypotonia can definitely be a problem ... If we walk down the street

**Table 2**  
Themes and Subthemes.

Main theme	Subthemes	Key findings
Developmental characteristics or condition related factors	Physical and cognitive traits	<ul style="list-style-type: none"> <li>• Mobility, gross motor and muscle tone</li> <li>• Cognitive delay and sensory impairments</li> </ul>
	Healthcare interactions	<ul style="list-style-type: none"> <li>• Oversimplified or depersonalized information</li> <li>• Increased medical care and appointments</li> </ul>
Social consequences	Influence on relationships	<ul style="list-style-type: none"> <li>• Parent relationships</li> <li>• Child relationships</li> <li>• Community resources and accessibility</li> <li>• Community resources influence on relationships</li> </ul>
Parenting influences and practices	Parent perceptions and adaptation to the diagnosis	<ul style="list-style-type: none"> <li>• Parental outlook</li> <li>• Parenting behaviors</li> <li>• Parental self-care</li> </ul>

she's okay, but if we walk farther than that, then she starts to get tired and she wants to be picked up and carried." Another parent explained, "Her balance is not very good at times, especially if she has to make a quick movement ... I think she kind of feels like sometimes she's going to get knocked over ...." Another parent described the challenges of participating in sports with muscular dysfunction, stating, "Well, his gross motor skills are not as developed as a typical 12-year-old, so at like lunch recess, if the 6th grade boys are out there and shooting hoops or catching a football, he can't do that, I mean he just doesn't have those skills." While certain physical traits had the potential to negatively impact a child's ability to participate in physical activities, parents also provided examples where the child's internal motivation to be active outweighed condition-related physical limitations. A parent of a child with spina bifida exemplified this when talking about her child who was involved in Paralympic Sports, stating, "He has done more and been involved in more things than most of his typical peers," but that prior to electing to use a wheelchair and stop using leg braces "he was always afraid of falling." Another parent stated that her child "gets aggravated" that she is not as fast as her peers, but that when she encounters an obstacle "she just finds a way around it." Some parents chose to engage their child in physical activities that took advantage of the child's condition-related traits: "I've always wanted him to do, because of his low tone, something that he's really, really good at. And so he's been taking yoga since he's been four, so I kind of feel like it's working with his strength."

*Cognitive delay and sensory impairments.* Compared to parents of children with spina bifida, parents of children with Down syndrome were more likely to report cognitive and sensory impairments. Overall, parents reported the presence of these impairments as challenges or barriers to the child's participation in physical activity and organized sports. One parent stated that, although her son enjoyed being involved in basketball, "We're a little trepidatious about the basketball experience, because it's competitive and he doesn't quite get the idea—you know, the concept of the game."

The associated sensory processing challenges and dietary preferences limited the child's dietary intake. Favored foods included "fries, chicken nuggets, bread, cheese and noodles." One parent described her daughter's approach to eating: "She appears to almost kind of try it out by putting things to her mouth to see, and I'm not sure if it's ... related to, like, how it tastes, or how it feels, or how she decides if she's going to eat it or not ... There's probably 10 to 15 foods that she eats on a regular basis." Another parent described her son's food aversions and preferences: "Like a yogurt texture, an applesauce texture he rejects, like oatmeal textures, he gags when he eats those ... he won't even do, like, a casserole at all, or anything mushy ... for a long time he only ate salty, you know, white things. So let's see, white pasta, white bread, white, it was white everything, white rice."

#### *Healthcare interactions*

Healthcare interactions were defined as the interactions between healthcare providers and parents to address weight-related behaviors of the child and to support the parents in managing the child's medical care.

*Oversimplified or depersonalized information.* During healthcare visits, parents of children reported inconsistent levels of discussion or resources from the providers on the topic of weight-related behaviors. One parent stated, "I think they have given me the healthy food things on maybe a flyer or brochure that they use, but as far as having a discussion about it which specifically regards to her, I don't recall ever having one." Another, who described her child as being "on the obese side right now," stated, "As far as our regular physician, they always give, like—not the food pyramid, whatever they use now ...." Another parent stated, "I love our pediatrician, but he's been kind of lax on the weight issue ... [he says] it's a side effect of the medication, you know, you're going to have

to provide healthier treats." When nutrition was discussed, the providers' dietary advice was often geared toward constipation prevention rather than optimizing weight. One parent explained, "The specialty [provider] we go to in Omaha, we're usually talking more about bowel stuff, such as the fiber intake and water intake and things like that. I mean, we talked about the 'eating healthy choices' type stuff, but I guess we haven't had to talk a lot about the diet."

While the majority of providers gave more general recommendations, some providers took a more individualized, client-centered approach, but often still lacked the information wanted by the parent. One parent stated of her daughter's pediatrician, "He was great. We were his only special needs child, so I know he did a lot of extra research to take us on and stuff. He was very willing that way." However, this parent clarified that she would have liked more information on community resources that were appropriate for a child with a developmental disability: "They didn't really have any resources to give us, like, 'Hey, you should go to the [program],' that kind of thing ... It's hard to actively seek that." Similarly, while discussing barriers to activity and exercise, one parent mentioned that her daughter's doctor stressed the importance of finding activities that promoted peer socialization, but that it was difficult for the parent to independently find age-appropriate activities: "The doctor had said that was a very, very important thing—to set up playdates. And I just don't—she doesn't want to do that ... so I don't know how to force her." When information was lacking some parents would independently search for resources. This was highlighted by a parent who sought treatment for her child at a pediatric weight management clinic. The clinic provided information such as sensory strategies for feeding and providing healthy recipes: "They did have new information and I got some new recipes. You know, they gave me a little game that you can play to try to get them to smell food, and taste food, and lick food, you know—different things just to get the food in the area of the mouth. You know a lot of the information is the kind of information that I already knew, but then there was a lot of other stuff."

*Increased medical care and appointments.* Parents reported increased interactions with healthcare providers through appointments and procedures related to the child's diagnosis. However, parents of children with spina bifida appeared to have more appointments with multiple specialists other than their primary care provider, especially during the child's younger years. Consistently, parents of children with spina bifida reported that their children's increased surgeries, need to use a urinary catheter for urination, and bowel programs interfered with daily routines and had a secondary impact on decreasing physical activity and directly increasing sedentary activity. One parent stated, "The times that he has to sit on the toilet for an extended period of time ... he really wears himself out and he's got to go lay down for a while." Another shared, "She's had hip surgeries and ankle surgeries and a lot of surgeries, so that sets us back so much of the time ... we'd have this big hip surgery and she'd be in a hip brace for eight weeks and then [have to] regain strength." Parents of children with spina bifida more often reported that medical routines increased their child's participation in sedentary activities, specifically screen time; five of the seven parents of children with spina bifida specifically stated that screen time increased due to their child's bowel program. According to one parent, "She has to sit on the toilet for about an hour, sometimes an hour and a half, while everything is cleaned out. And so generally that's why she has a Kindle or her dad's iPad." Another parent shared that her child's use of a knee extension brace to correct a contracture also impacted screen time: "I try to get her to do it [wear extension brace] at least an hour a day, if not two hours, and I have her watch TV while she's doing that because I'm like, 'I need you to be sitting.'"

#### *Social consequences*

Social consequences encompassed the direct or indirect social influences on the parent's ability to perform self-care or model healthy

weight-related behaviors for their child. These influences included the effect the diagnosis had on relationships, both within the family and externally with social groups or peers. These relationships were influenced by community resources, the accessibility of those resources and the perception of being judged.

#### *Influence of diagnosis on relationships*

Impact of diagnosis on relationships was defined as outcomes related to personal relationships of the parent or child that were perceived as being due to the diagnosis of spina bifida or Down syndrome. These outcomes affected the individuals' social support, daily routine and their access, ability or choice to participate in activities that promoted healthy weight-related behaviors. In the parents, this subsequently negatively influenced their ability to perform self-care and model healthy behaviors for their child.

*Parent relationships.* A primary outcome on the parent's relationships was social isolation which put strains on the parent and challenged their ability to perform self-care and role modeling activities. The social isolation partially stemmed from the perception of the child's behaviors being judged when in public, or a lack of understanding of the diagnosis and the time and expertise needed to provide special care. In regard to perceived social judgment, a parent stated, "In my area there are not a whole ton of kids with special needs and you can get a lot of, a look from strangers, and you know, ... if she is having a meltdown in the store, you know, and I've got people looking at me like, why are you letting this kid get away with this. ... So it, I think it does tend to deter me from getting out as often as I could maybe, just because I don't want to deal with the public."

The extra time for caregiving for the child related to the diagnosis (i.e. daily care, appointments, bowel programs) contributed to decreased social opportunities for parents with their friends or even their spouses: "We can't always get together because, again, you have to try to find caregiver and respite care, and that's not easy ... we just can't get a neighborhood kid to come over unless I train them in how to empty a bag ... I would say for the first five, six years of his life, my husband and I couldn't go out together because one of us had to be home, we had no caregiver..." Another parent stated, "My husband's a police officer so he works 12-hour shifts ... I mean I am the, you know, pretty much the—I don't want to say the—the primary caregiver, you know, when dad is at work ... You know a lot of times we're, like, we're stuck here because of [child's name]'s having a meltdown, or he's in a bad mood. We're stuck." Having resources available such as respite care was greatly appreciated; "...We're blessed to take part in the [respite program], so that has been a godsend... And that's helped a ton because we don't have any family in town. ... We could just have the day to go do—do normal stuff."

Some parents also noted how the increased childcare demands impacted their marriages: "And you can't put the blame on the child, and so sometimes the stress within a couple can be very, I guess it's kind of like, you know, you can take it out on each other, and it's hard, it just, it is hard...." Another shared, "We don't go out, we don't have dates... our focus has been on our children and, you know, in the last 14 years on [our child] and making sure he's healthy, and he's getting what he needs. And I know the divorce rates [are] very high with parents who have children with special needs, and I said it can either destroy you or bring you closer together, and thankfully for us it's brought us closer together and we are a good team."

In place of face-to-face social interaction with others, parents often used social media. As one parent stated, "I don't have a lot of friend time. I don't actually have a lot of friends. Mostly they're the friends that I have had since high school and the only way that we can keep in contact is on Facebook. Now Facebook itself has been an emotional lifeline for me and a place where I can get advice from other parents of kids with special needs. So you know, that's been a good support." Parents felt the isolation and limited time available to maintain

relationships affected their ability to provide self-care and to model positive weight-related behaviors in their daily lives.

*Child relationships.* Peer interactions had a large and direct effect on the child's weight-related behaviors, specifically participation in physical activity opportunities for the child. Additionally, options to be physically active were largely influenced by availability and accessibility of community resources and parental comfort with options.

When program opportunities were available, parents supported their children to participate and peer interaction was enhanced. One parent stated, "So many of these kids are so isolated and, like I said, the programs are few and far between but if you can find them and hook up with them, I mean can you imagine for my son who, part of his disability is bowel and bladder issues as well, he has to catheterize, and have a bowel routine and, you know, he has accidents occasionally, but here he is on a team with kids that are all doing the same thing. So he can say, 'oh, I got to go cath, I'll be right back', and nobody cares, and it's expected; whereas at school it's hush, hush, it's a big secret, he doesn't want anybody to know anything about that. But then he can finally feel like he's fully accepted for who he is when he's a part of a team with other kids dealing with the same things."

*Community resources and accessibility.* The reduction in physical activity opportunities for the child stemmed from a lack of resources adapted to the child's diagnosis, high cost or not geographically accessible. A discrepancy between the child's developmental and/or skill level as compared to their typically developing peers and additional responsibilities related to the diagnosis also impaired the child's ability to participate. "Unfortunately, the most central location for a lot of their activities is in [place], which is like 45 minutes away. So, when they have things in our home town we try to attend, but it's difficult to get to the other [location]." Another parent highlighted the wheelchair accessibility, "It's just tricky. You try to find that ahead of time if something is wheelchair accessible. And people don't have a true understanding of what that means. And it's not mal-intent, they say sure his wheelchair fits, when you get there and it's not for a power wheelchair."

When opportunities existed, parents or children were not always comfortable with them if the opportunities did not include peers of the same age or cognition level. One parent explained: "The [program] choices that I have right here in my neighborhood where we live, they have a lot of adults in there and I don't believe that [my son] should be playing with adults. I think that he should be given the opportunity to be able to play with his peers. And it, they can be typically developing or kids with disabilities, I don't care, I just want them to be kids of his age... I think he deserves peers." Parents of children with spina bifida generally stated that their child preferred to engage in activities with cognitively typical peers and strived toward typical social development. A parent described this as a barrier to her child's participation in physical activity: "One of my barriers was the [program]... I think there's a lot of people in those programs that have more mental disabilities, where hers is more physical and for some reason, in her mind, she doesn't categorize herself with having a disability that way ... They do offer things to do at the [program] and she doesn't want to participate in that because she doesn't feel like she fits into that."

*Community resources influence on relationships.* In most cases, the limited options for participation in physical activity left the child with decreased peer interaction. In these situations, caregivers or family members often filled the void. "The opportunities aren't quite as there, the spontaneous, unlike other kids, like he wants to do social things and he'll remind me, he knows that I'm the person who sets up social activities.... And then it's kind of fallen by the wayside, so he's developed more of a friendship with his babysitter. He's less likely, I think kids are - it goes both ways, I think sometimes they're both less likely to ... instigate a play date and make it happen. Like, and we don't really feel comfortable with him - so like whenever he runs out to play kickball like

we're always with him." Another parent shared, "His brothers play with him, again, being outside is tricky [safety], so we do a lot of inside activities, arts and crafts, that sort of thing, board games. But what in all honesty happens is it ends up being [him] with us as the parents, whoever is home with him, and his two brothers playing together outside." While the decreased options for physical activity programs directly correlated with the child's ability to be active and interact with peers, the replacement of family members in the peer role further decreased their own ability to have external social relationships.

#### *Parenting influences and practices*

This theme captured three types of responses including parent perceptions of the diagnosis, parenting behaviors, and parental self-care behaviors, each influencing the child's weight-related behaviors. In each sub-theme category parents reported both challenges and issues encountered as well as the strategies they used in response. These themes highlighted the underappreciated reciprocal or integral role that the parents had in the promotion or support of the child's weight-related behaviors.

#### *Parent perceptions and adaptation to the diagnosis*

This section was defined as parental perspectives related to the diagnosis of spina bifida or Down syndrome. The parent's perspective on the diagnosis influenced the child's weight-related behaviors through their parenting, advocacy of their child to participate in activities and their ability to provide self-care to themselves that shaped their own weight-related behaviors that were modeled for the child.

*Parental outlook.* The parent's outlook on their child's prognosis varied, with some parents describing sadness and others feeling hopeful and positive. This outlook translated to the parent's expectations of the child's involvement in different activities, the degree to which the parent chose to facilitate challenging activity or acquiesce to the disability with typical activities, and how the parent promoted other weight-related behaviors and habits linked to nutrition, physical activity and screen time. A consistent theme of wanting to empower the child was present. The child's diagnosis appeared to influence the outlook of the parents. One father shared his belief that "if you treat your child like they have some type of disability, they're going to have a disability. We've had a kind of theory since he was born that he's going to be raised as a typical child, obviously there's going to be some challenges here and there, but the way we treat him throughout the day, we're going to treat him as if he were a typical child and it's proven a plus on him and us." Another parent stated, "Well I just think we need to empower our children with disabilities that they can do anything they put their minds to with the appropriate tools, equipment, and support ... to feel a part of something." Even with a positive outlook, some parents expressed how their concerns amplified when they compared their child to other children:

"Like it can be great, and I'm so proud of him, but then they'll be something that just shows that he's not at the same level as like a 12-year-old is, and he'll never do some of these things ... chances are he will never drive a car ... he's a 12-year-old boy, and he's got some strong feelings about the girls ... I can be happy that I see that in my other kids but then it's kind of like a slap in your face realizing that that's not going to be his path."

One mother described the motivation her son had to find his own ways to adapt to situations and activities:

"And that's what we've always told the people around him, the teachers, neighbors, coaches, whoever, just talk to him and ask him how he thinks he might be able to do whatever it is everybody else is doing and he'll figure something out. We always talk about when he crossed over from being a Cub Scout to a Boy Scout, they do a ceremonial walk over this little bridge to symbolize crossing over to Boy

Scouts. Well, of course, this bridge was not wheelchair accessible. And my husband and I were sitting in the audience thinking, what is he going to do when they call his name, you know, we had no idea. They called his name, he flies up there, slams on his brakes, jumps out of his wheelchair, and crawls across the bridge as proud as he could be. You could have heard a pin drop in the entire place. And we were just ... lumps in our throat because, what a proud moment, he didn't care, he was going to get across that bridge like all those other boys, if he had to crawl, he had to crawl. It was pretty telling of who he is as a person that, if he wants to do it, he's going to find a way."

The combination of having an acute awareness of the challenges while maintaining the goal of preparing the child for the future prompted parents to advocate for and empower their children. A mother of a child with spina bifida spoke about advocacy, "my only goal throughout everything I've been through with him is to make him a strong person and somebody who never sees their disability as an inability." Another mother said, "We've taught her that just because you have spina bifida doesn't mean that you're different from other people. It just means you do stuff differently, so physical activities and stuff like that." One mother spoke of her attempts to foster independence in her 11-year old boy with Down syndrome and his unknown future. "I'm trying to constantly look at the whole picture of his life, am I giving him enough opportunities for independence...it's almost like a sculpture that you have to keep turning to see, if I have all the sides covered." One parent's optimistic outlook translated to wanting to de-stigmatize spina bifida by educating educate others on the positive attributes of her children and how the challenges of living with a disability did not define his identity.

"So we, we are sharing our lives with people, and that's why I was glad to participate in this study, because there's no reason for anybody to feel alone or to feel depressed or disheartened that they're going to have a child with spina bifida, because it's been the most wonderful, and hard, and painful, and difficult, and joyful, and, you know, every emotion you can imagine, 14 years for us, but it's been, we wouldn't change it. We don't want our son to go through hard times, but he's a phenomenal young man and he has a lot to offer in this world."

Even with a positive outlook, some parents acknowledged that the future outlook could be disheartening. Some parents of children with Down syndrome expressed the recognition of the condition as life-long with decreased improvement in cognitive abilities and independence for their child at adolescence or young adulthood. One mother of a 12-year old with Down syndrome reported, "It feels overwhelming, thinking about the future, and if you think too far ahead, that becomes like just almost scary. Like you know what he's going to be like as an adult, and where he's going to live, and what kind of job he's going to have..." A mother of a 6-year old with Down syndrome shared, "They have problems that aren't going to go away and it makes you sad..." Parents of children with spina bifida found increased challenges during their children's younger years, but expressed that their children established routines and independence with age.

*Parenting behaviors.* These were defined as the parenting responses and behaviors of parents in the study, especially those parenting responses and behaviors related to addressing their children's conditions. Parenting behaviors translated to weight-related behaviors in different ways.

Parents discussed the need to choose their battles with their children, and how this impacted both the parent's ability to do what they know they should do for their child's health and the parent's own well-being. Food was often used as a reward for children across both groups in the study and is consistent with parenting of children of all abilities as well. Many parents worried about not role modeling optimal

health habits. A number of parents talked about the need to role model healthy behaviors related to eating and exercise. One mother stated “If you want your kids to be healthy, you have to show them the healthy side. You have to do it, so they do it.” One mother talked about her challenges with role modeling healthy eating when she was stressed: “If I don’t have time to eat because I’m dealing with him or his therapy, I’m sure he sees me reach for a cookie or a soda.” Another mother stated, “I think both [husband’s name] and I have always been very active people, and our ability to get to the gym and work out has been limited by—by [child’s name]’s needs.” Another reported, “...We’ve tried the pediatrician’s recommendations, you know, carrot sticks or pieces of fruit, but ... he will not work for fruit. And he’s really highly motivated by the snack foods and stuff. So really, it sounds horrible, but to get him to ... comply and do a lot of things ... our [therapy aid] has him right now working for ... an M&M at a time or whatever.”

**Parental self-care.** This was defined as the ability to care for one’s own needs in the face of caring for a child with special needs. This influenced the parents own weight-related behaviors and at times resulted in unhealthy coping mechanisms which can have unintended consequences for the child’s behaviors.

Parents described their energy levels often as focused on the child and therefore less for their own needs. A mother stated, “I spend most of my mental efforts on taking care of my child and my husband and there is not a lot left over for myself. I tend to use food as an analgesic.” Another parent shared, “I know as a parent that I don’t do a lot of things for myself. When I went to this camp last week, a lot of these parents made me realize that I need to be taking care of myself. Of course, my way of taking care of myself is to get a yummy ice cream or something... It’s a food thing because I’ve always - my whole life, I’ve turned toward food for everything. ... I think that I’m very conscious about not showing that to my kids. ... I don’t want them to learn that habit because I know it’s not a good habit.”

Interrupted sleep was a common theme for many of the parents with younger children and for children with cognitive delay. One mother shared, “sleep is difficult ... she can have a very wonky sleep schedule and it can be very difficult for me to manage time taking care of all the household needs, time taking care of her, time spent ... just alone with my husband and to get enough sleep to really be a functioning human being.” Another parent emphasized that the amount of time devoted to medically managing the child’s condition can negatively affect parents’ abilities to care for themselves: “And so our son had 16 surgeries in the first four years of his life. In the first year it was like 150 some doctor’s appointments and seven surgeries. And we’re talking three therapies a week, and you know, it was just very consuming, very consuming. And, yes, the parent’s needs are always on the back burner.”

## Discussion

This study provides the perspectives from 15 parents of children who are diagnosed with either Down syndrome or spina bifida. Through open-ended questions related to 1) the child’s weight-related behaviors of nutrition, activity (physical and screen), 2) the healthcare provider influence on managing the child’s weight, and 3) parental self-care and role modeling of healthy behaviors, valuable information was shared and consistent themes emerged.

Through analysis of the parent’s perspectives, the child’s diagnosis of Down syndrome and spina bifida, the provider’s management of weight and their own behaviors and ability to provide self-care had both directly and indirectly influenced the child’s weight-related behaviors. Inherent traits or characteristics of the diagnosis appeared to have direct implications on the child’s participation in physical and sedentary activity and their nutritional choices. Participation or non-participation was partially influenced by the child’s coordination, mobility and muscle tone. These traits were perceived as challenges or limitations to

participation in physical activity. Of all weight-related behaviors, physical activity participation created the most discussion by the parents in our sample. Parents highlighted multiple concerns that needed to be addressed for their child to participate in physical activity. Finding an activity that was adapted to their child’s cognitive or physical ability was a challenge that was exacerbated by the family’s geographical location, financial means, and accessibility issues. A parent pointed out that what may be considered as wheelchair accessible to someone without a disability was not always accessible to the child. On the other hand, when programs were available, parents were not always comfortable with them for their child or the children themselves were not comfortable. A specific example included a program that has a wide age range of participants provoked concern and frustration from the parent as they preferred for their child to be grouped with others in his own age group. Another program that incorporated various intellectual or physical disabilities was seen as a negative to the child who only had a physical disability, as they did not feel like they fit with all of the participants.

In certain instances, a change in mobility that may be assumed to restrict mobility actually facilitated increased activity. Contrary to the common concern that pediatric use of assistive devices may cause a functional decrease, evidence suggests that assistive device usage has a largely positive impact upon function and quality of life with few negative effects (Henderson, Skelton, & Rosenbaum, 2008; Rosen et al., 2009). In spina bifida, a child may initially ambulate independently or with orthotics. As the child ages and progressive lower extremity muscle loss occurs, ambulation may become more challenging and often painful. In our sample, a parent eloquently stated how this transition to a wheelchair actually increased the child’s ability to be active and have more opportunities to participate in physical activity. When activities were adapted to the child’s ability (i.e. gym) or when the child participated in activities that capitalized on their strengths, (i.e. Down syndrome and yoga) the parent perceived that the child’s experience and the overall impact on their wellness was positive. Previous research has indicated that wheelchair use by adults with spina bifida indicates restricted ability to participate in social activities and activities within their communities (Barf et al., 2009; Dicianno, Gaines, Collins, & Lee, 2009). However, studies on pediatric power mobility use show mixed results indicating that children using power wheelchairs may show increased functional capacity, independence, and social opportunities, as well as causing decreased stress for the parent (Livingstone & Field, 2014). Further study is needed before conclusions can be drawn.

Nutrition was influenced indirectly by the child’s sensory processing difficulties that limited the variety of the child’s diet (i.e. decreased fruits, vegetables, textured foods) and an increased dependence on processed foods. This is important as it can be difficult to change or expand a child’s dietary choices once they are established. As one parent did point out, when she took her child to a weight management program, the program provided intense education on initiating new food choices in small steps with consistent exposures. Nutrition was also indirectly influenced by bowel irregularities or constipation that commonly occurred within the group; thus, bowel health had an indirect positive effect on the child’s diet as there was an increased focus on diet being discussed and recommendations focused on fruits, vegetables, water and fiber intake.

Other than focusing on nutrition related to constipation, healthcare providers generally did not provide specific recommendations for diet and activity specific to the child’s condition or in an individualized manner. Often times, the health care provider gave very general suggestions such as provide healthier treats or provided standardized handouts related to the food pyramid or nutrition. Overall, the parents did not express frustration with the varying level of support for weight-related behaviors, with the exception of wanting more specific recommendations about programs or activities that would be a good fit for their child and the child’s condition. In essence, they wanted the provider to individualize the recommendation to their child. For example, one provider stressed the need for the mother to enroll the child into a

program to provide peer interaction, but the child did not want to do this and the mother expressed frustration about not being able to follow through on the provider's recommendation.

Interactions with healthcare providers were not limited to traditional annual visits; the children in our sample, particularly the children with spina bifida, had an increased number of interactions with healthcare providers secondary to their subspecialty needs or surgical interventions. While these increased appointments allowed more touch points with providers, they did not increase the discussion on weight-related behaviors. Conversely, they inadvertently fostered increased participation in sedentary behaviors including screen time. Bowel management programs associated with spina bifida and recovery time from surgical procedures were repeatedly associated with the child having "down" time, and this time was usually made more palatable by providing the use of a screen. While the recommendation is to limit or balance screen use for children (AAP Council on Communications and Media, 2016), no professional organizations provide specific caveats or alternative recommendations for when a child needs to be still or inactive for a period of time, as was the case for some of the children with chronic health conditions described in this study.

Participation in physical activity and movement is promoted early in a child's life and can foster socialization with peers. As the child enters the school system, physical activity programs often revolve around sports or games. In elementary school, inclusiveness is a priority including implementation of programs that promote "buddy" systems allowing all children to be involved in activities. As children age, the competition related to these activities becomes more pronounced and the focus on a child's ability becomes a predicate to participating. As these changes occur the inclusivity of these programs that center on sports and games becomes secondary, limiting opportunities for children with disabilities to be an active part of a team, outside of being an accessory role such as the water boy. While this hampers the child's participation in physical activity, it also creates barriers for peer socialization. In this sample, when the inability to play or participate with others was not possible related to their abilities, parents and siblings often filled the void of the peer and would "play" and "interact" with the child. This also occurred due to safety concerns and the parents need to be present.

During interviews, parents expressed strong beliefs and attitudes about raising a child with a disability that influenced their child's weight-related behaviors, particularly participation in physical activity. Most parents integrated their beliefs and outlook for their child to consciously empower their child or advocate for them. While many strong statements were shared by parents, one parent summarized that they chose to not treat their child as if he had a disability because then he would have a disability. They instead focused on raising him the same as a typically developing child which they feel has been a benefit. Parents attempted to instill strength in their child, not let the disability define them and to foster their independence. A parent specifically told her daughter that she was not different due to her condition, but that she did things differently. Concurrently, children often exhibited their own empowerment and internal motivation by adapting to a situation versus waiting for a situation to adapt to them. Further studies would be required to determine to what extent the child's outlook was influenced by the parent's outlook.

During discussions about parenting their child with a disability, some parents shared that there were unique challenges that complicated even the most positive outlook, or that varied based on the age of the child. Parents of children with spina bifida generally expressed a decrease in daily parental responsibilities as the child aged. Parents of children with Down syndrome had more mixed views on their child's independence, with some parents displaying a high level of optimism and advocacy for autonomy, and others worrying that this was out of reach. A specific concern shared by parents of children with Down syndrome was the unknown trajectory of their child's condition, which

made it difficult for the parent when they considered the child's future. This concern was exacerbated when the parent compared their child to other typically developing children who were the same age. The recognition that their child with Down syndrome may not experience many of the same developmental events as other children created a sadness for the parent. Parents recognized how their unique insight and expertise in caring for their child was a valuable resource that could be used to educate others and advocate for their child. This recognition often led to the parents offering to be a resource for other parents of children with disabilities or finding ways to promote an understanding of their child's condition.

During discussions surrounding the ability to care for themselves and role modeling healthy weight-related behaviors for their child, parents in this sample provided a thoughtful picture of the extra challenges that they encountered. Parents acknowledged that their own engagement in habits related to food or activity would affect their child. Some parents identified that they did not always engage in healthy habits so they would make an effort to either not have the child observe potentially unhealthy habits (i.e. stress eating) or make a stronger attempt to engage in the healthy habit (i.e. exercise). While this thought process was present, daily stressors sometimes created challenges in the ability to execute this plan. Specific challenges included the additional responsibilities required to care for their child. Some of the responsibilities necessitated training or specific skills (i.e. catheterizing) which they felt limited their options to have others do for them. They also noted that not having enough time in the day to complete all tasks often influenced their sleep routine and energy levels.

Parents noted that the ability to cope with the stressors included the use of food as a coping mechanism. Within this sample, the majority of parents interviewed were overweight or obese, whereas there was more variation in the children's weights. This is an important point for two reasons. Research in children who are typically developing has supported that children of parents who are overweight or obese have a higher likelihood of becoming overweight or obese (Fuemmeler, Lovelady, Zucker, & Østbye, 2013; Whitaker, Wright, Pepe, Seidel, & Dietz, 1997). In addition, children who are obese in their adolescent years are more likely to remain overweight or obese in their adult years (Biro & Wien, 2010; Whitaker et al., 1997). As the mean age of the children in our sample was 9.3 years, there is a higher potential for the percentage of children who are overweight or obese to increase and remain in adulthood.

In addition, the increased daily care and responsibilities the parent encountered sometimes created relationship challenges leading to a sense of social isolation. A parent from a small community did not think that other parents understood her situation and that if her child had a meltdown in a store that she would publicly be judged for this. This parent's perception led to her not going out in public with her child as often, creating a sense of social isolation. Other parents expressed that the increased responsibilities that needed their attention created an inability to have ongoing social relationships with their own peers and even in their marriage. Some parents turned to social media to fill the void of social face-to-face interaction. Other parents spoke positively of the use of respite care and how that small time away from their child allowed them to spend valuable time with their spouse or engage in normal activities like getting coffee and promoted self-care. The inability to perform parental self-care included the inability to participate and perform their own healthy weight-related behaviors. This is critical as role modeling of healthy behaviors can influence and support the adoption of these behaviors by the child.

## Limitations

The small sample size of this group was a limitation to the study. Additionally, the interviews only elicited the perspective of one parent, whereas there are a multitude of parties involved in the care of children with disabilities. This only allowed the team to hear a portion of a

family's story. Future studies focusing on the weight-related behaviors of children with disabilities and their families should attempt to elicit the perspectives of the child, both parents, siblings, and other family members or regular caregivers. In addition, children with other disabilities such as muscular dystrophy or Prader Willi Syndrome have an increased prevalence of obesity. Future studies should focus on other diagnoses to provide a broader picture from the parent's perspective. It is also important to note that the sample consisted largely of college-educated parents with financial security. Further research should examine a more socioeconomically diverse group to truly understand issues of access and resources that influence families of children with disabilities.

Additionally, weight-related behaviors are influenced by multiple variables. Future studies should attempt to identify personality characteristics such as resilience, intrinsic motivation, self-efficacy and coping strategies that may provide a more complete picture into the weight-related behaviors of the child and family members and provide direction for future interventions. Adaptive strategies and resources varied among families, and there was no singular successful set of strategies or resources reported for child weight management with either diagnosis. Certain programs that worked for some families were deemed ineffective or mismatched to the child's needs by other families, and types of providers that were helpful for one family might not be helpful for another. A closer examination of family approaches to adapting tasks and routines is recommended for future research. While the findings from this study confirmed awareness and concerns of the risk of obesity with their child, the interview questions did not allow us to describe or elicit the parent's level of motivation or interest in wanting to make changes. This could be examined in future research when exploring options for interventions. The phenomenon of interest within this study was the parent's perspective of how the child's diagnosis influenced the child's weight-related behaviors. The choice to include parents of children with two distinct diagnoses, both with a heightened risk of obesity, added depth to this study's data set. While significant differences were identified between groups (i.e., the influence of the bowel program on children with spina bifida or the parent's safety concerns for children with Down syndrome), the similarities in parent perspectives illustrate a consistent pattern of needs and concerns (i.e., struggles with parental self-care, desiring more personalized health education from providers, tendency toward social isolation, reliance upon accessible community resources for activity and social support) shared by parents of children with disabilities. The results of this study will add to the science of weight management and children with developmental disabilities, as well as to the clinicians' abilities to anticipate the needs of the families.

The authors of this study collected data on both parental and child demographics as it is known that parental weight-related behaviors influence child weight-related behaviors. (Must et al., 2014). However, there is a lack of evidence examining the link between parental stress, caregiving of the child with a disability and obesity. Results from this study support the need for analysis of this link, as the majority of parents interviewed were overweight or obese and commonly cited lack of time for self-care, lack of respite care, and stress eating as challenges in their day-to-day routines.

## Conclusion

Examining parent perspectives on how a child's diagnosis, specifically spina bifida or Down syndrome, influences the child's weight-related behaviors of nutrition and activity (physical and screen) reveals complexity and a variety of challenges both socially and medically for these families and children. There are opportunities for healthcare providers to positively influence a child's physical activity and nutrition and provide support and recommendations when medical needs create challenges in daily routines. Promoting parental self-care and validating the emotional aspects of parenting a child with special needs are aspects

of healthcare that appear to require further attention from clinicians. Recognizing the complexity of raising a child with a disability and attempting to manage weight-related behaviors on a daily basis within the social and family context are critical areas needing additional emphasis in pediatric research.

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**Michele Polfuss:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Validation, Visualization. **Caitlin Dobson:** Formal analysis, Methodology, Validation, Visualization. **Kathleen J. Sawin:** Formal analysis, Methodology, Validation. **Carol G. Klingbeil:** Formal analysis, Methodology, Validation, Visualization.

## CRediT authorship contribution statement

**Michele Polfuss:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Validation, Visualization, Writing - original draft, Writing - review & editing. **Caitlin Dobson:** Formal analysis, Methodology, Validation, Visualization, Writing - original draft, Writing - review & editing. **Kathleen J. Sawin:** Formal analysis, Methodology, Validation, Writing - original draft, Writing - review & editing. **Carol G. Klingbeil:** Formal analysis, Methodology, Validation, Visualization, Writing - original draft, Writing - review & editing.

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