Single-Method Research Article

"Unable to Feed My Hungry Child": Experiences of Mothers Caring for Children With Prader-Willi Syndrome

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Abstract

Mothers' experiences of caring for children with Prader-Willi Syndrome (PWS) is largely unknown. With no treatment for PWS, parents undertake (extra)ordinary care practices to keep children safe from overeating and self harm. Knowledge of these care practices could lead to effective interventions. Narrative inquiry was used to study everyday experience with Canadian mothers. Participants cared for a child 3 to 17 years old who had hyperphagia. Participants were interviewed 8 to 12 times each over the course of a year. Narrative accounts were co-composed through a collaborative process of analysis. Engaging with participants' everyday experiences amplified complex care needs for families and gaps in health and social care systems. Narrative threads focused on engaging in (extra)ordinary care practices, rigid care work to keep children healthy and safe, tension from others while enacting these care practices, and difficulty conforming to social expectations with childrearing and care work. Recommendations for practice and policy include (a) shifting from untenable care practices, (b) reconceptualizing care work, and (c) alternative care models.

Keywords

Prader-Willi syndrome, rare disorders, neurodevelopmental disorders, mothers, children, lived experience, medical complexity, narrative inquiry, Canada

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There is little known globally about mothers' experiences of caring for children with the rare genetic disorder, Prader-Willi Syndrome (PWS). PWS requires lifelong care from parents and others in meeting care needs (Miller et al., 2011). While children are living with their parents, this care requires keeping children healthy and safe from overeating and self harm. For a mother living with a child who has PWS, these care practices become ordinary. Yet, their practices are extraordinary in addressing the unusual behaviors and the responsibilities to keep their children safe, as well as affording them opportunities to interact with others (Currie et al., 2024). As such, these become what we have called (extra)ordinary care practices. There is a need for nurses and other health care providers to understand the everyday tensions, medical and social complexities, and lifelong accountability and responsibilities of mothers caring for a child with PWS.

Caring for Children With Prader-Willi Syndrome

Prader-Willi Syndrome (PWS) is a rare, complex neurodevelopmental disorder. Characteristically PWS causes substantial health, behavioral, and social challenges, with one of the most difficult challenges being hyperphagia and anxiety. Disabilities for children include cognitive, physical

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(mobility, speech, feeding, gross and fine motor challenges), mental, and learning (Miller et al., 2011). Hyperphagia involves a dysregulation of appetite satiation within the hypothalamus and aberrant perceptions of and reactions to food (Cassidy et al., 2012; Driscoll et al., 2017; Miller et al., 2011). Hyperphagia symptoms include insatiety and food seeking, which begins between ages 3 and 13 years and continue into adulthood (Heymsfield et al., 2014; Miller et al., 2011). Children are predisposed to genetic obesity (Butler & Thompson, 2000; Schwartz et al., 2021). Hyperphagia requires hypervigilance from parents and caregivers (Mazaheri et al., 2013; Tan et al., 2020). Children with PWS also experience moderate to severe neurobehavioral issues characterized by perseveration, repetitive behaviors, lying and manipulation, arguing, and temper outbursts (Mazaheri et al., 2013). To date there are no medical treatments for this syndrome and families are often searching for physical or psychological support to manage the complexities of child development, behavior, and medical care (Tan et al., 2020).

After diagnosis of PWS, parents are often left to manage the unrelenting manifestations of hyperphagia, anxiety, and other medical and behavioral challenges with few supports. With no known treatment for PWS, changes to physical and social environments become necessary. Parents are instructed to provide rigid practices by the medical community which become part of necessary care work. Care practices are the physical, social, and emotional work, largely taken up by mothers, and are influenced by larger sociopolitical and social factors (Armenia, 2018). Managing care practices with PWS becomes very challenging for parents with the need for rigid care practices in all environments and the risk of life-threatening consequences with food in many social settings (Allen, 2011; Bedard et al., 2023).

Mothers of children with disabilities often face barriers and stigma from gendered and ableist ideologies of mothering and care with dependency (Huang et al., 2023; Kittay, 2011; Knight, 2013; Nishida, 2022; Piepzna-Samarasinha, 2018; Ryan & Runswick-Cole, 2008). Further, care for a dependent child by mothers and families is undervalued, unremunerated, and underestimated but essential in preventing institutional care, health care costs and expenditures, and keeping children healthy and alive (Ennis, 2014).

Mothering is influenced by the “good mother” ideology which is the most popular conceptualization of mothering (Green, 2015). Mothers caring for children with disabilities are even more affected when the stakes are higher with children who require continuous care needs. “Good mothers” are responsible for the health of their children (Fierheller, 2022). They campaign, advocate, and fight as warrior mothers and superheroes against structural inequalities for services and medical care for their children (Runswick-Cole & Ryan, 2019; Sousa, 2011). Mothers caring for children with chronic conditions that require regular care, can rarely change the medical and behavioral outcomes for their children. They are placed in a conflicted position of keeping their children healthy and alive with lifelong dependency on others.

Most care practices go unnoticed by others and are generally unknown for a child with neurodevelopmental challenges such as PWS (Tabatabai, 2020). These unique care practices are essential to manage the hyperphagia, food certainty, food security, anxiety, and obesity their child will experience. Many mothers restrict food and only offer it within structured and predictable routines. Mothers offer low caloric, low carbohydrate, and low sugar options (Butler et al., 2019). Environmental management also includes withholding food, locking fridges and cupboards, managing access to food in every setting, and always supervising the child. Mothers care for their hungry children by denying them food to preserve their health and wellbeing.

There is little research on the experience of parents caring for a child with PWS within the global literature (Allen, 2011; Čagalj et al., 2018; Chaij et al., 2014; Reilly et al., 2015). There is, however, a need for health and social care professionals to understand how mothers, as primary caregivers, manage day-to-day care. This narrative inquiry focused on the following research puzzle: What are the experiences of mothers caring for a child with Prader-Willi Syndrome? What is it like to mother a child with constant hunger and hyperphagia? How do ideals of good mothering shape the experiences of mothers of children with PWS? During this inquiry, the shared stories and dominant social stories of parenting, motherhood and care practices were expanded and reshaped through ongoing conversations with participants.

Methods

Narrative inquiry is situated in the work of Clandinin and Connelly (2000) and is the study of experience. Narrative inquiry is both a methodology and a phenomenon under study (Connelly & Clandinin, 1999). Narrative inquiry is influenced by Dewey (1938), who believed knowledge arises from inquiring into everyday experiences. As such, the knowledge sought by narrative inquirers is situated in everyday happenings for people who are living their lives. Everyday experience influences how we see others, our futures, the world, and ourselves (Clandinin & Rosiek, 2007). Dewey (1933) noted the importance of being aware, present, and curious about experiences. Dewey argued for studying experience unfolding over many moments in time, as an authentic source for constructing knowledge, understanding, and enacting social change (Caine et al., 2019; Clandinin & Rosiek, 2007). This everyday knowledge is seen as useful and purposeful as we interact and respond (Dewey, 1925; Rorty, 1999). As well, inquiring into everyday experience provides insight into social, cultural, and political influences surrounding experience (Clandinin & Rosiek, 2007).

Recruitment

Mothers were recruited from the Canadian Foundation of PWS and a provincial PWS Facebook parent group using purposive and snowball sampling (Creswell, 2013); they were invited to participate if they were caring for a child with genetically confirmed PWS from various regions in Canada. Participants engaged in conversations with the first author, who was conducting her doctoral research, over a 12-month period. With the onset of COVID-19 and the long duration of the pandemic, conversations shifted from in-person to virtual. Four mothers of children with PWS participated in the study to tell, retell, live, and relive their stories and provided a composition of life experiences (Estefan et al., 2019). The typical sample size for narrative inquiry is three to five participants (Clandinin, 2013) which offers longer-term engagement with participants and depth of insight into experience, rather than breadth of agreement about a phenomenon (Lessard et al., 2015).

Data Collection and Field Work

Prior to commencing the study, written informed consent was obtained. Ethics approval was granted from the University of Calgary (CHREB # 21-0761). The inquiry involved 8 to 12 conversations (60–90 min in duration) with each mother over the course of a year, beginning in July 2021. Within the inquiry, connections, time commitments, and boundaries were negotiated with participants (Clandinin, 2013). Participants could withdraw from the study at any time; they provided ongoing consent to be part of the study. Conversations were audio recorded and took place over a secure internet platform. Conversations were transcribed by the first author and data were saved on a password protected server.

Mothers were asked to reflect on their experience. Questions covered a range of topics regarding daily events or happenings that related to management of hyperphagia and care practices involving food. For example: “Can you describe how your daughter displays hyperphagia?” “What was the experience for your child and family in celebrating Thanksgiving with extended family?” “Can you tell me about your experience of the next-door neighbor’s birthday party that your daughter was invited to?” Data or field texts (Clandinin & Connelly, 2000) were composed from transcripts of research conversations, letters mothers had written to others about their feelings surrounding care practices and PWS, field artifacts such as pictures, mementos, personal items (Clandinin, 2013), and mothers’ own journal writing. Some of these artifacts were used in the narrative accounts produced in the study to highlight experiences of daily life (Clandinin, 2013). Names of participants were changed for anonymity.

Data Analysis and Interpretation

Through an engaged and collaborative process of analysis, field texts and interim research texts were co-composed within a cycle of clarifying, reading, rereading, and interpreting field texts alongside participants (Clandinin & Connelly, 2000). Narrative accounts were co-composed with participants (Clandinin et al., 2015). This was done by sharing texts with mothers, and they provided input and feedback into the interpretation of the transcripts and writing of the text (Clandinin, 2013). Attention was given to the narrative inquiry dimensions of sociality, place, and temporality.

Positionality Statement

This study was completed by the primary author as part of the requirements of her doctoral thesis. She is a white female, born and raised in Canada, and holds several degrees in nursing. As a researcher she brings the experience of her gender, social, economic, and cultural lenses, and her professional development to her work. She recognizes her positionality is shaped by her privilege and access to resources, and she stives to be aware of her own biases and assumptions and recognizes how these may shape her research.

Participants

Mina, Cherie, Helene, and Giuliana told their stories and shared everyday human moments that added to our learnings and understandings of caring for a child with PWS. All participants lived in Canada, but in different provinces. All the mothers identified as Caucasian. Three of the families had French as their first language in addition to English. The mothers were between 35 and 50 years of age and identified as she/her. The mothers all had high school education and three mothers had some postsecondary education. The mothers were married, but one lived apart from her husband through the week because of her husband’s employment. All mothers had some employment but managed the care needs of their children with PWS, which affected their type of employment. Two families experienced some financial pressure with caregiving needs and lack of maternal full-time employment. All mothers were the primary caregivers for their children with PWS within their families. Fathers of the children were involved in their children’s care but there was delegation of sibling care with the care responsibilities of PWS. As well, navigating and coordinating daily care and medical and social care appointments most often was the mother’s responsibility. The children with PWS were all diagnosed several weeks after birth through genetic testing and ranged in age from 7 to 17 years of age at the time of the study. Three of the mothers had other children without PWS. All children required 24/7 caregiving from the family and others such as in home, school, and community environments. None of the children with PWS could be left unsupervised at any time.

Results

Engaging with and listening to participants' stories over time revealed tension and complexities within the experience of caring for children with PWS. In this inquiry the daily experience of caring with children living with PWS was explored with four mothers and the complex social relations and emotional work of mothers was made visible. Narrative threads resonated across participants' stories and showed some of the challenges in caring for a child with PWS. Mothers' stories provided a window into the reality of day-to-day experiences managing the complexities of PWS with behaviors such as hyperphagia and anxiety, food insecurity and lack of food certainty (children being anxious that there would be no food even if there always was), and health risks associated with PWS such as obesity and death.

Engaging in (Extra)ordinary Care Practices

As holders of knowledge (Rich, 1976), mothers shared care practices which had to be adapted and transformed so their children could engage and participate in the world. These were ordinary everyday practices for mothers but were extraordinary for others. Nuances were identified within these threads and are grouped under (extra)ordinary care practices and include overwhelming rigidity, challenges with care in relation to food, hyperphagia and medical care, managing behaviors, and social conformity.

Overwhelming Rigidity: "We Have Rigid Social Norms". With the diagnosis of PWS, mothers were instructed by physicians and nurses to use specific rigid care practices to manage hyperphagia, prevent overeating and the onset of gross obesity, and other associated health problems. When given the diagnosis of PWS, participants outlined the overwhelming focus on the risks of hyperphagia, insatiation, and food seeking. The mothers were fearful about their child's weight and behaviors if they did not uphold rigid care practices. Helene described her reaction when the geneticist gave her medical literature about gross obesity to read.

> *I think when I read that document I wasn't thinking about Dani, really, I was thinking about myself—you know what I mean? It is an awful thing to say, but in hindsight it was a very self-centered reaction where I am going to be living with this monster and I was afraid of who she was going to become and that she was my child.*

Within the mothers' private worlds were stories of mothering and caring for children who were always hungry and trying to get food. Mothers established practices where food was restricted and only offered at specific meal or snack times with structured and predictable rigid routines. Food was not used to satiate an appetite or nurture or comfort a child. Mothers had to be rigid about the types of food offered and the environmental management of food. Cherie shared about the rigid norms in her home.

> *I think the hyperphagia existed and exists now as well, but I think we have these rigid social norms that we have created within our house that allow us to have a little less anxiety, stress, and focus around the hyperphagia. We had a period where she was stealing things from our pantry and we locked, and we had a period where she was eating the cat food and we locked that as well.*

In the families there were no second helpings offered, strict portion sizes were used, and food was not offered if not on a strict schedule.

> *We were told by the PWS association to never give her seconds. So, from the age of 18 months, we never have. We don't offer her any food between meals and won't let others give it to her either. We have been called out by others that surely just this once won't matter. Well, it does matter, as she won't forget about it.*

Challenges in Caring for Children in Relation to Food: "Food Dominates My Thinking.". The focus of care for mothers in managing their child's hyperphagia was supervising access to food in all environments to keep their children healthy and alive. Mina shared the need to lock her kitchen door.

> *I don't know if I am doing the right thing. I know for certain for my piece of mind so that I can sleep in my house I have to lock it [kitchen door], otherwise she would be . . .I feel like she would just eat all the time, right?*

Participants' children were always hungry and often seeking food. As an element of caring, mothers had to deny food to their hungry children. Mina relayed the unexplainable tension of not being able to feed her hungry child.

> *That is the worst part, I think, like I can handle the stupid meltdowns, the hundreds of questions, the rigid behaviours, the weird nuances, but the crying for food and having to deny your kid that basic need to survive, and it is so real for them.*

Helene also depicted the focus of food in her home and the impact on her experience as a mother with rigidity around food practices. "*Food dominates her [Dani's] thinking, and at a certain point I realized that* that is *my life. Food dominates my thinking.*"

In addition to tension with behaviors and food regulation, there was also tension for mothers outside of the home with hypervigilance and social management required in social surroundings. Helene's life was unequivocally changed with the focus on food security and managing every environment for Dani.

> *I couldn't relax, I couldn't, even in a place where they were trying to make it safe for them, ultimately it was chaos, you know? I am exhausted after that and then it is time to come home and I don't want to go to people's houses anymore, I don't want to socialize! It is much easier to have people over here at our house where everything is just controlled.*

Food is often considered a way to connect and relate with others through caring and sharing. Helene further expressed the challenges with venturing into public with a child with PWS in relation to social expectations around food. "*There are events happening and people invite us, but I don't want to go places because everyone is just itching to give kids a cupcake, or candy, or a donut or something and I feel afraid, you know?"* The management of hyperphagia required a commitment to change everyday feeding practices for everyone in the family before symptoms began to appear. Mina specifically shared her rigidity around food with early adoption of care practices which included extended family.

> *Like for us we knew that it was going to be hard for our family to adjust to the new food style, right? So we started right away [shortly after diagnosis] in holiday gatherings and things like that changing our patterns so we would have a really good foundation with the family so when it was a problem with Sadie it wasn't a problem with Sadie and the family trying to get them to change their traditions, right?*

To care as a mother with a child with PWS, was to uphold rigid rules and regimes even when others questioned the inflexibility of the rules. Mothers had to attend to the dangers of food for their children. Mothers shared that family, grandparents, friends, schoolteachers, healthcare providers, and respite workers did not always understand the care needs for a child with PWS. This led to social tension for mothers and for others. Cherie elaborated on the associations others have with food, even when they were aware how food was a trigger for their children. As Cherie shared, "*I don't know, but there is this attachment to food and love or something, and they [family] feel* that is *the way they need to express it. . .. there are all these emotions attached to food."*

There was also a sense of disbelief and a lack of recognition of the struggles by others when they witnessed a glimpse into families' private lives. Helene shared her embarrassment with having others over for dinner—memories of her daughter having a melt down at the dinner table resurfaced. "*I kind of want to be like, "She is not a monster!" You know, she is being monstrous, but she is not a monster!"* This was the third time the word monster was used by Helene as a connotation to how others outside of the family might view her child with PWS because of incoherent behaviors from expected social norms. Giuliana also described her sister's discomfort about her parenting practices and not understanding the full weight of caring for a child with PWS. Her sister would say to her "*I can't believe a mum would say that to their child*." Giuliana felt others expected parents of special needs children to be responsible for their children and manage all the challenges.

> *I think you will never feel as judged as a parent, and then you add special needs parent, and you are just judged so much more . . . it all falls back on us and then of course we are going to feel like shit because it is something we didn't do right.*

Giuliana had decided to not be as restrictive with her daughter around food choices. She felt her daughter's behaviors were easier to manage if she ate what other people were eating and had more food to eat. There was tension when Giuliana described her decisions not to follow a strict diet regime, nor obsess over food labels, and to follow different practices than other mothers within the PWS community. These decisions also came with shame and self-judgment. "*I am on the other camp, like she has had cake, she has had candy, she has even had chocolate milk, and then I feel this small, you know* [gesturing with her fingers]?" Conversely, Giuliana discussed her thoughts about other mothers' decisions to be restrictive with food choices for their children. "*I would probably judge other mums who are too restrictive because I think it is going to bite them in the ass in the end, but they would probably judge me because of Keely's weight."*

Care practices surrounding management of hyperphagia were particularly difficult because many social activities are connected to food. Socializing and celebrating with food are considered a normal part of everydayness. Giuliana relayed there was food everywhere. "*And it is all about the food. Every get together."* Helene referred to food as "*landmines*." She discussed her angst with the lack of food security and the risk for her daughter to participate in social activities. She shared that the onus was on her to not miss anything as inevitably other parents missed things.

> *I feel like it will come across that I am telling people that there is something wrong with what they are doing because of our experience, and it has to come across that way because the whole point is like, you know, your house cannot be safe enough, it just can't, because you don't even see the things that are a danger as a problem.*

Giuliana also communicated her frustration when others invited them to their houses and their kids were eating different food choices then her daughter could eat. "*I am sure my kid is going to love some applesauce when you guys are chowing down on an ice cream sundae!"* Mina shared her efforts to manage the social environment with others which led to further social isolation. "*We have started asking people, like, hey, we can't come if you have food all over your house. We just can't."*

Hyperphagia and Medical Care: "What Did I Do Wrong?" Mothers followed prescribed medical and social rules of caring for their children which were monitored by the medical and social care communities. There was tension around managing their children's weight. Growth charts and frequent weight checks reduced mothers' hard work and hypervigilant caregiving to parameters of weight and height on a growth curve. Giuliana shared the focus on weight, *"We gauge how well we are doing as a mother with the weight of our kids because* that is *all we know about with Prader-Willi Syndrome*, that is *where all the focus has been, on the weight, right?"* If a child was seen as overweight it was likely an indication of poor parenting management as communicated from the medical, school, and PWS community. As Giuliana shared, "*She is a big girl. . . If you look at my girl and I am like, what did I do wrong? It gives you an indicator but doesn't give a true indicator maybe of the types of bodies that PWS represents."*

With such a focus on hyperphagia with PWS, mothers indicated they felt weight had become a measure of whether parents were correctly managing hyperphagia as parents. Mothers said they compared their children to other PWS children to assess if their child was typical within the PWS community. A child carrying extra weight was a visible indicator of whether mothers were being stringent enough and their child had access to too much food. Giuliana described how weight was a measure of mothering ability particularly within the PWS community. *"We gauge how well we are doing as a mother with the weight of our kids because* that is *all we know about with Prader-Willi Syndrome."*

Against the norms of care work for mothers with a child with PWS, Giuliana decided not to restrict some food options so her child would not miss out on normal interactions with others around food. Giuliana expressed the tension to not follow strict regimens that excluded her daughter from doing things other kids could do. She did not believe in providing the suggested structure, routine, and schedule of eating and meals for her daughter, as this did not prepare her daughter for unexpected changes. Giuliana was comfortable with her daughter being a little overweight as she felt it helped her daughter not to have major behavioral issues of food seeking and acting out from hunger.

> *All I can do is I would rather she be a little bit overweight than not have the major behaviours. I would rather she be bit overweight and not food seek. That is what I would want. Now would I want her to be 50 pounds under? Sure. Will that be possible? I don't know.*

Giuliana's decision to not restrict food options was challenged by physicians, nurses and others as insufficiently caring for her child.

When physicians and nurses inquired about hyperphagia as a symptom of PWS, mothers expressed there was still no support. As Helene shared, "*What are you going to do if I tell you yes, it is terrible hyperphagia? So, what do you do for me now? You just take note of it?"* Mothers expressed frustration that, beyond focusing on weight alone, there was no further support for managing the unrelenting hyperphagia and anxiety.

Caring for Children's Challenging Behaviors: "We Have Gone Through the Grabbing Off People's Plates". Mothers also shared (extra)ordinary practices associated with managing anxiety, self-injurious behaviors, argumentativeness, inflexibility, rigidity, and poor emotional control with temper tantrums, aggression, and meltdowns. These behaviors were persistent, disruptive, and overwhelming in everyday life. (Extra)ordinary practices were embedded in rigid routines that were normalized and ordinary within the PWS community. Mothers shared many small moments of trying to engage in everyday life with a child with PWS. Giuliana shared, "*Behaviors can escalate. The behaviour, sometimes everything is going well and then suddenly a switch goes off and you are like, why are you acting this way?"* These routines were established and maintained in the family and were adhered to as a way of reducing meltdowns and reactions. As Cherie shared, "*We have a sequence of events* that is *listed, even written down, and we function with a sequence of events*."

These behaviors carried on in the home. Home was a place for temper tantrums, arguing, and perseveration about minor issues, severe skin picking, and aggression. Cherie shared her daughter's self injurious behaviors.

> *We have gone through the grabbing off people's plates and the screaming and the yelling. I guess that is where we sit with hyperphagia that it is there, but I would not say that is our greatest concern at all, like I would say the anxiety and the . . . some of the aggression are far greater—like aggression towards herself and her self-mutilation—I would say those behaviours are far more disconcerting for us than hyperphagia.*

A home environment is typically linked to comfort and feeling safe and relaxed. In the case of PWS, common mothering practices included close monitoring of children and elaborate management of all home situations to keep children safe from life threatening behaviors.

There was also tension that socializing and inviting others into the space could reveal the hidden difficulties of PWS such as temper tantrums at dinner, obsessing about the menu options, trying to grab other people's food, demanding more food, and not giving up on these requests. For the mothers in the inquiry, this led to social tension and ultimately isolation. Mothers were reluctant to expose their private space. Mina shared that behind closed doors in her home was where Sadie displayed the most behaviors.

> *Sadie on lots of occasions can appear normal, right? And then it is only kind of behind closed doors that she kind of lets loose! And then it is like when you try and describe it people are like, well that is not the image of her I see here, and they don't connect the dots.*

Within the home environment, there was no sanctuary, nor a soft place to land. There was social pressure to not discuss these behaviors that often escalated around normal routines and not exhibit them in public spaces for fear of a reaction from others.

Pressure to Meet Care Practices: Social Conformity and the "Mom Mafia." The mothers in the study also discussed having select friends and family members to share holidays with and manage the difficulties with hyperphagia and anxiety. Other friends and family had expressed discomfort with the rigid food routines or were not comfortable with the (extra)ordinary care practices. Mother's stories revealed that they were often living in circumstances that were radically different from how other families lived their lives. This became alienating for the mothers who were living outside of "normal" narratives of family. It was also isolating for those who were outside of these experiences and did not know how to relate to them. The mothers shared the importance of building other connections, but they also highlighted the difficulty in doing so. Mina shared some of the alienation: "*I don't want all my friends to only be parents of kids with special needs. I want to have friends like the friends I had before I had Sadie*." Mothers worried that their children would be rejected by others because of their incoherent behaviors. As Mina said, *"Oh God . . . will people still love her if they see her like this? So, it is a bit of protecting of her, right?*"

Parents used Facebook parent groups for advice and guidance from other mothers since little was known about treatments and interventions for PWS. There was a sense of vulnerability and reliance on others' experiences since there are so few people to whom they can turn. This reliance could also lead to judgment if a mother did not follow the suggested prescribed regimes for diet, schedule, and behavior management from the PWS community. This judgment sometimes brought isolation, disconnection, and fracturing of relationships with others in the community when mothers tried something different. This was particularly troubling for the mothers who were practicing untenable care practices for their children and yet experienced judgment within their own PWS community when it was perceived they were not being "good enough mothers." Giuliana mentioned she was a "*lurker"* instead of a full-time visitor to the Facebook groups because of her experience of isolation and exclusion. Giuliana talked about alienation from others on the Facebook group for choices made about food security and locking the fridge. Helene also talked about how food management choices for children with PWS was a polarizing topic due to different perspectives on low carb, low calorie, sugar free, ketogenic, etc., diets. There was no empirical evidence if one diet was better than the other in curbing hunger and blood sugar surges, but there were strong opinions from the mothers on Facebook groups.

> *I do find the Facebook world kind of a scary world too because there are some opinions, thoughts and feelings in those spaces I find alarming and disturbing. . . Yeah, I think that choosing the sugar-free diet is weird because I did choose that diet, and like technically it is a choice, and I feel that is a source of much of our social isolation, choosing to do that because sugar is so ingrained in our society.*

Cherie explained why she thought parents were judgmental about each other's decisions on how to manage the syndrome. "*So, in judging each other, aren't we defending ourselves?"*

Giuliana had chosen to make different food choices for her daughter than other mothers on the Facebook group. She felt her daughter had less maladaptive behaviors if she was not as rigid around diet choices and treats. She felt her individual experience and her knowledge of her child were not honored within the PWS community. She had sought support from several other mothers who had children who were overweight and were disillusioned by how they were treated on the main Facebook group. Giuliana believed they needed a judgment free zone and a place to share their realities, so they formed their own small group.

> *And then I created a little bit of a Facebook group with three mums who are of similar feelings like, for Keely that we are little bit with kids on the heavier side, but like-mindedness in terms of that, and where this is a judgement-free zone, where you are like, "Oh yeah, they got into that," like got into the candy or treats.*

Mothers also expressed that few parents shared in the Facebook groups if their child was doing well because of possible resentment and jealousy within the PWS community. Cherie stated: "*You are scared to tell the world how bad it is, but you are scared to tell the world how good it is because those are normal feelings we have."* When asked if she would share on Facebook if her child was doing well Mina said, "*I mean no. I probably wouldn't feel comfortable because I would feel I was maybe perceived as boasting, or something."*

Giuliana shared why some mothers did not reach out for advice about food management from other mothers on the Facebook group, "*They are afraid to go on Facebook because of the Mum Mafia. The Mum Mafia will be there with their pitchforks, you know?"* Overall, the findings revealed polarization from others when mothering a child with PWS.

The mothers' stories held insight into the work of nurturing, caring, sustaining, and contributing to the care of a child with PWS and the (extra)ordinary care practices that are involved with the tension to be a "good mother."

Discussion

The mothers' stories troubled, reshaped, and refashioned our understanding of the difficulties in maintaining care practices for a child with PWS. Although these practices were ordinary (Dewey, 1925) and expected as part of care work for mothers (England, 2005), they were (extra)ordinary considering the intricacies and peculiarities of caring for a child with PWS. For a mother living with a child who has PWS, these care practices are part of an ordinary day. Yet, their mothering practices are (extra)ordinary in addressing the unusual behaviors and the responsibilities on mothers to keep their children safe, as well as affording them opportunities to interact with others. Longitudinal engagement with mothers in this inquiry showed the nuances of everyday life when caring for a child with PWS. The mothers' stories add to a greater understanding of the unique challenges for the child with a complex disorder and their family in participating in ordinary life. The findings extend our understandings of PWS beyond medicalization of the disorder and illustrate the responsibilities, accountabilities, and care work required so children with PWS can participate in life.

The inquiry provided an amplification of the intersection of the care needs of children with PWS and the gaps in health and social care systems. The tensions and challenges that were exposed in the inquiry spoke of inadequate support for families. Building on the mothers' experiences, three key recommendations and implications for re-envisioning care work were co-developed, namely, moving beyond untenable care practices, reconceptualizing care work, and providing appropriate support through social ecological models of care.

Untenable Care Work and Care Practices

Mothers' stories of difficulties adhering to medically and socially determined care practices in the management of PWS—as suggested by medical providers and reinforced within the PWS social community—warrants attention. Mothers of children with PWS are caught in a bind of being unable to offer satiation and nurturance to their hungry children, and having to uphold rigid care practices for their children that go against more typical mothering practices (Ruddick, 1989). The associations between socially constructed concepts like mother, food, and care coalesce as "good mothering but are fraught with tension and contradictions when caring for a child with PWS.

Mothers shared they felt judged socially and morally if they could not manage or sustain high standards of care, an experience that has been observed among other mothers caring for children with chronic health problems (Brehaut et al., 2019; Woodgate et al., 2015). If their child was carrying too much weight, this was seen as an obvious physical difference from normative and desirable standards, because responsible care is framed as the need to restrict children's food to avoid childhood obesity (Maher, Fraser, & Lindsay, 2010). In addition, children with PWS have one of the highest incidences of maladaptive behaviors over most other neurodevelopmental disorders (Kayadjanian et al., 2018). Mothers in this study expressed many instances when they could not meet unrealistic, untenable care practices and management of behaviors for their children. They also felt judged by health and service care providers (physicians, nurses, and disability workers) if they voiced this difficulty. This finding aligns with the work of Sprague and Hayes (2000) who discussed socially preconceived expectations about care work, how these care practices are devalued, and dependency on women to silently fulfill these roles. In this study, mothers who did not adhere to the care practices also felt on the periphery of the PWS community and isolated both medically and socially. Conversely, mothers also felt on the periphery of neurotypical communities if they rigidly upheld care practices as others did not understand they were essential to the health of their children.

Parents who did not comply with the rigidity of the practices often lacked support to manage overwhelming constraints in living one's life. An onus on the mother and family to adhere to rigid practices without the necessary support led to overwhelming responsibility and expectations that were perceived to be unrealistic and unattainable, and ultimately fostered guilt and shame. Friedman et al. (2021) and Ennis (2014) referred to specific behaviors and expectations of the "good mother," particularly with the intersection of identities, in this case mothering and lifelong caregiving. Disciplinary knowledge must shift and adapt to move in ways which are supportive for caregivers who must maintain rigid care practices for their children to be healthy. Nurses and other health care providers need to consciously resist dominant medical and social discourses that hold mothers and parents of children with PWS responsible for their children's weight, behaviors, and overall health outcomes (Friedman, 2015). An unhealthy weight gain might be an indicator of families needing more support in managing behaviors, and a larger issue than weight management (Reilly et al., 2015).

Reconceptualize Care Work Beyond Individualized Care Practices

Care work must also be reconceptualized. Mothers expressed social isolation and lack of regular engagement with others outside the home from managing hyperphagia and adherence to care practices. There are other complex neurodevelopmental disorders that involve difficult care practices and have similar medical, social, and behavioral challenges to PWS (Baker et al., 2018; Gardiner et al., 2018; Huang et al., 2023; Reilly et al., 2015). Neysmith and Reitsma-Street (2005) suggested that, socially, the responsibility and ultimate care work of women includes feeding and providing nourishment to children and their families. However, our findings extend these understandings of mothering and caring for a child with PWS related to food and nourishment and highlight the need to reframe how we think about *care* when food is both a need and a source of potential harm.

Mothers in this study were expected to manage their child's disability often in isolation and often could not have the same kind of social relationship and social experiences with their children or with others. This aligns with other literature on the experience of care work when mothering a child with disability (Blum, 2007; Brock et al., 2015; Tabatabai, 2020). Care work needs to move beyond an individualistic response where families are solely responsible for managing and caring for a child with complex needs, to an interdependence model of care which is relational and reciprocal (Tabatabai, 2020). According to Page et al. (2020), most care practices in North America, Europe, and Australia for children with complex needs are the responsibility of the immediate family at home. This can be isolating for families who live away from extended family and social support networks (Bradshaw et al., 2019; Woodgate et al., 2015). We recommend that research and practice priorities could be redirected to co-designing health services and systems with families, through ongoing conversations, that are meaningful, inclusive, and provide a space to share perspectives (Fayed et al., 2018; Smits et al., 2020).

This shift to a relational way of knowing includes discussing strategies and approaches that work for families and can influence everyday health and well-being. For example, this could include a shift from focusing on a child's weight and growth parameters to discussion of participation in everyday life and supports that parents would find helpful and meaningful based on their choices and abilities (Georgiades & Kasari, 2018). This perspective aligns with P. L. Rosenbaum and Novak-Pavlic (2021) who suggested a move toward determining interventions that support the child and families' developmental capacities, rather than concentrating on limitations.

Support Through Social Ecological Models of Care

(Extra)ordinary mothering practices are more than adaptation and resilience to difficult, sometimes unimaginable circumstances. These practices are also about parenting amid a lack of support for mothers of children with complex neurodevelopmental disorders and a reliance on individualistic approaches to managing associated care needs. There has been little examination of larger systems and structures that continue to hold mothers and families responsible for unrealistic care needs (Knight, 2013). Our study suggests there needs to be a holistic and integrated outlook on health and well-being for the family beyond medicalized narratives (P. Rosenbaum & Gorter, 2012).

At a community/societal level, there is a need for greater acceptance of children with neurodiverse behaviors (Georgiades & Kasari, 2018). This acceptance needs to be paired with realistic and effective supports so children and their families can engage and participate in everyday life (P. Rosenbaum, 2009). Neurobiological impulses mean children with PWS have little success in controlling or stopping their own behaviors (Singh, 2022). Therefore, when it comes to managing behaviors such as hyperphagia (Thomas, 2021), a shift is needed away from pathologizing to building and providing appropriate supports, structures, policies, and systems to support mothers and manage difficulties.

Targeted policy interventions could include reconceptualizing care models to remove systemic barriers to ensure PWS children have equitable opportunities to reach their maximum level of health and wellbeing. This includes a view toward social ecological models of care that consider the relationships between the physical, mental, and social health of children and families that encompasses the entire life-course. These models require integration of family, community, environment and health and support systems, social structures, and policies that assists mothers and parents in the care of PWS and participation in society (Bach, 2017; Filipe et al., 2021). This also involves disrupting neoliberal ideologies of individual responsibility and resiliency, toward developing systems of support as a collective social responsibility to support and sustain interdependence for mothers, children, and families caring for a child with complex needs (Brant, 2014; Douglas et al., 2021; O'Reilly, 2016; Piepzna-Samarasinha, 2018; Runswick-Cole & Ryan, 2019; Tabatabai, 2020). Fulfilling recommendations such as these will require mothers' voices in the co-design of systems of support through research, policy, and practice in addressing care priorities and an integrated outlook on health and well-being (Pozniak et al., 2021; P. Rosenbaum & Gorter, 2012; Smits et al., 2020). Our study also suggests this includes managing conflicting and changing individualized priorities for the family caring for a child with PWS over time and circumstances.

Strengths and Limitations

The strengths of this study include that it offers an increased understanding of the unique nuances of everyday life when caring for a child with PWS. Four mothers gave rich descriptions over the course of a year about their experience of care with PWS. There are several limitations in this study which could be addressed in future research. Concerted efforts to increase the diversity of participants with regards to ethnicity, SES, educational level, and the gender and age of children with PWS could extend our understanding of mothers' experiences and contributing factors. Future studies could also include the experience of male caregivers and siblings. Notwithstanding limitations in some areas of data representation, results from participants across interviews were consistent and alternative responses were included in the data.

Conclusion

This inquiry into the experiences of mothers caring for children with PWS reveals previously unknown stories of the complexities and nuances of specific care practices. Mothers in this study were unable to satiate their children's hunger and monitored and restricted their children's food intake to keep them healthy. These (extra)ordinary care practices were challenging, socially isolating, and difficult to maintain; a situation made more difficult for mothers and families because of the lack of adequate support and understanding. There is a need to engage families in co-designing a response to care that includes approaches and strategies that work for them. Too often, systems and structures hold mothers and families responsible for meeting unrealistic care needs. There is also a need to reconceptualize mothering norms and caring practices. This includes making room for difference and diversity within the social and theoretical landscapes while supporting families. The expansive understandings of everyday care practices in this study offer insight into how to better support parents and their children with PWS to function and participate in everyday life.

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