

Walking in the shoes of caregivers of children with obesity: supporting caregivers in paediatric weight management

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What is already known about this subject

- Family caregivers play a prominent role in multicomponent paediatric weight management programmes.
- Most studies have captured caregiver perspectives about weight management programmes at treatment initiation, completion or treatment withdrawal.
- Embedding feedback opportunities for family caregivers into various stages of programme development might allow for exploring the psychosocial complexities of caring for a child with obesity and the associated treatment implications.

What this study adds

- Caregivers reported feeling isolated and blamed for causing their children's obesity.
- Caregivers appreciated the supportive forum that group-based programming provided for sharing experiences.
- Paediatric weight management programmes might consider including peer support opportunities and discussion forums for ongoing social support in addition to education about lifestyle change.

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Summary

To incorporate the perspectives and experiences of family caregivers of children with obesity, the KidFit Health and Wellness Clinic, a paediatric weight management programme, embedded feedback opportunities into various stages of programme development. Caregivers were eligible to participate if their children had completed initial 4-week group-based pilot programming or were currently receiving treatment in 10 or 12 week group-based programming. Data were collected through feedback session discussions, audio-recorded, transcribed verbatim and analysed thematically. In total, 6 caregivers participated in the pilot group feedback session and 32 caregivers participated in the structured group feedback sessions. Caregivers reported that healthy lifestyle strategies first communicated by clinic staff to children during group sessions provided expert validation and reinforcement when discussing similar messages at home. Caregivers reported feeling isolated and blamed for causing their children's obesity and appreciated the supportive forum that group-based programming provided for sharing experiences. Since experiences of blame and isolation can burden caregivers of children with obesity, paediatric weight management programmes might consider including peer support opportunities and discussion forums for ongoing social support in addition to education about lifestyle change.

Keywords: Paediatric obesity, patient-engagement, quality improvement, stigma.

Introduction

Multicomponent lifestyle interventions for childhood obesity that include dietary and physical activity modifications and utilize behavioural strategies with family-based behavioural and parent-only behavioural treatment types have proven efficacious (1–3). Since family caregivers play a prominent role in these well-established treatments, seeking the input of caregivers is critical for the effective delivery of behavioural treatment (4,5). While most studies have captured caregiver perspectives at treatment initiation (5,6), completion (7) or treatment withdrawal (4,8–15), with feedback specific to intervention approaches (6,12,13,16,17), barriers to treatment (12,13,18,19) and reasons for attrition (4,8–15,20), few studies have captured caregiver experiences related to the psychological and social ramifications of having an obese child (21–25).

Caregivers of children with a chronic disease can experience courtesy stigma (25–28), in which a person is stigmatized or subject to negative social judgment or blame because of his close association with another person with a stigmatizing feature (29). Given the social discourse that attributes the responsibility of child weight management to caregivers through food and exercise choices (30), it is likely that caregivers of children with obesity might also experience courtesy stigma (31). Therefore, when developing a paediatric obesity treatment programme, it is important to incorporate caregiver perspectives and experiences into the content and delivery of the programme.

In the initial development of the KidFit Health and Wellness Clinic (KidFit), a multidisciplinary, paediatric weight management programme at Trillium Health Partners (THP) in Mississauga, Ontario, the team adopted the position that engaging families in programme development by integrating their values, experiences and perspectives could enhance service optimization (32,33). For the purposes of programme development, family engagement was defined as patients, caregivers and health professionals working in active partnership, in programme design and care delivery to improve health and wellness (33). The objectives of this report are to explore the caregiver perspective of the psychosocial complexities of caring for a child with obesity and the associated treatment implications.

Methods

Setting and programme development

KidFit is one of 11 hospital-based paediatric weight management clinics funded by Ontario's Ministry of Health and Long-Term Care. Launched in 2015, KidFit is a 2-year, group-based treatment programme. Children between 2 and 17 years old are referred by a physician (typically the primary care provider) for obesity (body mass index

≥ 95th percentile for age and gender on the 2000 Centers for Disease Control and Prevention Growth Charts for the United States or ≥97th percentile on the World Health Organization Growth Charts for Canada). The development of KidFit as a paediatric weight management programme reaches beyond the singular outcome of weight loss and includes a holistic approach to overall health and wellness for children and families. There are no programme costs to the families.

KidFit assesses between two to four new children each week. In the initial stages of KidFit development, following a multidisciplinary intake assessment with a paediatric endocrinologist, nurse, mental health provider (either a social worker or child psychologist), dietitian and an activity therapist, referred families were invited to participate in either a 4-week pilot Preteen group (caregivers and children in grades 6–8) or a 4-week pilot Teen group (caregivers and children in grades 9 and above) that were held in November–December 2015. The pilot groups were held weekly with required attendance by at least one family caregiver in addition to the child. Following the pilot phase, KidFit implemented a process whereby referred families were scheduled to attend an information session to learn more about the programme prior to enrollment. Following the information session, interested families were then scheduled for an intake assessment. In March 2016, KidFit launched more structured group-based programming with three groups with enrollment according to the grade of the referred child: (i) Juniors group held weekly for 10 weeks for caregivers of children in grade 5 and under and (ii) Preteen and Teen groups held weekly for 12 weeks for caregivers and children in grades 6–8 and grades 9 and above, respectively. Since there was more content for the Preteen and Teen groups, these programmes were longer than the Juniors group. During these sessions, families learned healthy lifestyle strategies from the multidisciplinary team including healthy eating, physical activity, coping with stress and parenting. Families with more complex needs or for whom group would not be appropriate due to significant behavioural challenges or mental health problems were offered individual sessions with the mental health care providers, activity therapist, and dietitian. This project was deemed a local quality improvement project and exempted by the THP Research Ethics Board.

Programme feedback sessions

Feedback sessions were conducted with caregivers of patients enrolled in KidFit, who had completed the 4-week pilot group-based programming or who were currently enrolled in the more structured group-based programme. Participants consented to audio recording during the feedback sessions.

Data collection

All caregivers from families that participated in both the pilot and more structured KidFit group-based programming were invited to participate in a total of seven feedback sessions. Caregivers from families enrolled in the 4-week KidFit pilot groups (Preteen and Teen) were contacted by telephone by members of the project team and invited to participate in a combined feedback session after the completion of the 4-week pilots. Similarly, caregivers from all families enrolled in the 12-week Preteen and Teen groups were invited to participate in feedback sessions in the middle (week 5) and near the end (week 10) of their group-based programme (Table 1). Additionally, caregivers enrolled in the 10-week Juniors group were invited to participate in feedback sessions in the middle (week 4) and end (week 10) of their group-based programme (Table 1).

Feedback sessions were led by experienced facilitators. A semi-structured discussion guide was used across all three groups. Questions were related to the following topics: (i) overall experience with the group programme; (ii) educational topics covered and learning styles and (iii) desired next steps in the programme (Table 2). At the beginning of each feedback session, participants were told about the importance of their feedback and opinions in regard to programme development, that there were no 'right' answers, and that we wanted to hear from everyone. Detailed field notes for each feedback session were taken to provide background and context. Demographic data were not collected for participants in the combined 4-week pilot feedback session. These data were collected for participants in the structured group-based programming feedback sessions.

Data analysis

The data were analysed using thematic analysis (34–36) involving five steps: (i) reading across and becoming familiar with the data; (ii) developing codes based on the data; (iii) organizing codes into themes; (iv) naming and describing the key themes and (v) creating an analysis. Engaging a line-by-line coding approach, three team members

Table 1 Caregiver feedback session details

Feedback session type	Number of participants
Mixed Preteen and Teen caregiver after 4 week programme	6
Teen caregiver mid of 12-week programme	12
Preteen caregiver mid of 12-week programme	12
Junior caregiver mid of 10-week programme	5
Teen caregiver near end of 12-week programme	11
Preteen caregiver near end of 12-week programme	6
Junior caregiver end of 10-week programme	4

Table 2 Caregiver feedback sessions interview guide

Questions about overall experience
What do you think about the group sessions to date?
What has stood out as something you enjoyed?
What has stood out as something we could improve?
What are your thoughts on the amount of time you have spent with your children during the group sessions?
Questions about educational topics and learning style
What are your thoughts on the amount of hands-on activity in the sessions so far?
Of the content covered thus far in group sessions, what information have you found useful?
What is an important topic that you wanted to learn about that we did not cover?
In what way (if any) is your life different because of your participation in the group sessions?
Tell me about your experience with applying the information learned in group.
Questions about next steps in programme
How frequently would you want some type of contact (weekly, biweekly, monthly)?
How long should the next phase of the programme be (e.g. 12 weeks or 6 months)?
In the next phase of the programme, would you want more structured sessions on specific topics or would you prefer less structured sessions that focus more on offering peer support and help with implementing what you have learned?
Would you be interested in participating in a group that is open to other KidFit families (not just the ones in this current group)?
Would you prefer closed group sessions where you stay with the same people you have who participated in group with you?

independently reviewed the transcripts and then met to reach consensus on a coding framework that was applicable across the feedback session data. Transcripts were coded using AtlasTi, a qualitative data management software programme (37). Themes and patterns across the coded data were identified and discussed. Views and observations of team members were recorded as reflexive memos to support the emergent analysis (38).

Results

Caregivers from 11 families were invited to attend the combined feedback session after the pilot groups. Of those families invited, six caregivers from four families participated. Caregivers from 30 families enrolled in the structured group programme were invited to attend the feedback sessions. Of those invited, 32 caregivers participated. At least one caregiver from each family attended a minimum of one feedback session during the structured group programme. Demographic data for 3 of the 32 caregivers were not available. The demographic data for the remaining 29 caregivers are listed in Table 3. The duration of the feedback sessions ranged from 30 to 75 min. Three interrelated themes were identified that highlighted key opportunities and challenges for family caregiver

programme participants. The themes were: (i) the importance of delivering and reinforcing healthy lifestyle messages; (ii) caregiver experiences of feeling blamed for causing their children’s obesity and (iii) the value of a supportive forum for sharing experiences related to caring for children with obesity.

The importance of delivering and reinforcing healthy lifestyle messages

Caregivers reported that healthy lifestyle strategies first communicated by clinic staff to children during group sessions provided expert reinforcement. Caregivers felt supported and validated by the healthy lifestyle education provided by the KidFit team. As a participant noted:

‘If it comes from me, automatically it’s a fight but [it’s okay] if it comes from the other side’.

Another participant reported that it was easier for her to discuss certain topics with her child when the information had already been provided by clinic staff during educational sessions:

Table 3 Sample characteristics for participants in structured group feedback sessions (N = 29)

Category	Grouping	n
Sex	Female	22
	Male	7
Age range	20–39	3
	40–49	18
	50 and above	8
Marital status	Married or domestic partnership	25
	Single	4
Educational background	High school	7
	University	18
	Postgraduate	4
Family household size	1–2	1
	3–4	17
	5–6	9
	>6	2
Ethnicity*	Caucasian	12
	Latin American	2
	South Asian	4
	Southeast Asian	2
	West Indian	2
	Arab	4
	Filipino	3
	Canadian First Nations	1
Household income	Less than \$49 999	5
	\$50 000–\$79 999	8
	\$80 000–\$99 999	6
	\$100 000 and above	7
	Unknown	3

*Participants were able to select more than one ethnicity.

‘And I also find that when we’re at home it’s so much easier to get her to sit and listen to things that have been backed up here. It’s because the teacher said it, because the counsellor said. It’s so just so much easier to bring it back up again when you get home and to try things’. (Preteen Caregiver 1, P1)

Additionally, participants appreciated the inclusion of special family sessions within the programme to recognize the importance of family dynamics in implementing lifestyle changes:

‘Yeah, it was good that it was family inclusive because, you know, it’s a family issue, you know. It’s a family change, a family lifestyle change. So to include everybody was – and not just making this [my son’s] issue, it became something that the whole family could make a change’. (Preteen Caregiver 2, P1)

Caregiver experiences of feeling blamed for causing their children’s obesity

Caregivers commonly described perceptions of being ‘judged’ as a ‘bad parent’ by others and strongly sensed that their child’s obesity was perceived by others to be their responsibility and under their control. One participant reported how she felt blamed by her paediatrician for causing her son’s obesity:

‘You know, the fact remains I was getting blamed for everything. Even the paediatrician was saying, “Well, you buy it, it’s your fault.” And I’m thinking, “Excuse me?” I mean, you know, I grew up in a household where yeah, we bought junk food, we bought this. But my mom said, “You don’t touch that, that’s for company, you don’t touch it.” And nowadays.... I hide it and I put things away and I do have a sweet tooth, but I’m trying to teach him self-control’. (Teen Caregiver 2, P3)

Another caregiver specifically spoke to the added burden and of caring for a child with obesity. This participant’s observations also speak to the feelings of isolation that parents of children with obesity may experience:

‘Yeah. It’s, you know... To say that no one walks a mile in a parent of a heavy kid’s shoes, than another heavy kid’s parent. It’s true’. (Preteen Caregiver 2, P1)

Value of a supportive forum for sharing experiences related to caring for children with obesity

Caregivers valued the group sessions as a forum for sharing experiences related to caring for children with obesity, and expressed the need for ongoing support following

programme completion. Participants described the group meetings as an opportunity to share their parenting experiences in a non-judgemental setting. One participant expressed comfort in knowing that she was not alone in the challenges encountered around family dinners:

‘But I think us sharing our experiences is a really important part of it because that’s where you find out you’re not alone. You’re not being [judged] – the thing you thought that, “Oh my God I’m the only one who does this!” Like I forget who it was that said it but “We don’t eat sitting around at the table.” So but then my husband’s like, “Well other families do.” And then I’m like, “Not every family does.” So you know, it’s to that point where it makes you feel like you’re not alone and you’re not that bad, you know what I mean?’ (Junior Caregiver 1, P5)

Participants also discussed how they and their families would maintain positive changes after completion of the first phase of the programme. An individual communicated the need for follow-up sessions and ongoing support:

‘So, I mean, we’ve got a fantastic program here, but, you know, kind of like we’re talking about graduation from the program, what’s going to kind of happen after graduation, and I guess one of the concerns that I would probably have is, you know, is there something that’s going to help us just keep maintaining things? Is there, like a follow-up or something like that and also being part of something so we don’t just...’ (Preteen Caregiver 1, P4)

Discussion

During the feedback sessions, caregivers consistently reported that prior to participating in KidFit, efforts to encourage behavioural change in their children had been met with resistance and dismissal. In fact, caregivers of young children may hide the need for weight loss due to concern that their children might experience stigmatization while parents might be more direct in their communications with older children with the understanding they should assume more responsibility for their health (39). After enrolling in KidFit, caregivers perceived that their own messaging about health and wellness to their children had greater impact if reinforced by the KidFit providers. Moreover, caregivers felt supported and validated by educational content presented in the group-based sessions and some reported less conflict about healthy eating at home. Children with obesity often perceive healthy behaviour messages from caregivers as negative and respond better to positively framed messages (40). It is possible that the children in KidFit may have been more receptive and conflict reduced because KidFit provides and models messages in a positive approach and environment. Additionally, several

of the KidFit educational sessions focused on improving communication between caregivers and children. These sessions included changing the language used when talking about weight and healthy lifestyle. Although caregivers spoke to the importance of the KidFit expert voice, in actuality, the combination of positive messaging and communication skills sessions helped caregivers to feel more confident in their parenting approach. Despite the perceived improvement, the caregivers spoke to the overall difficulty of behavioural change and expressed the need for ongoing support to maintain lifestyle changes after programme completion.

During the feedback sessions, participants discussed feelings of personal responsibility, blame and social judgement related to their parenting. Since caregivers can be regarded by others, including healthcare providers (23,41), as directly contributing to or primarily to blame for their child’s obesity (25), the communication of these feelings in a discussion forum are not unexpected. These sentiments are consistent with stigmatization (42) that can play a prominent role in the experience of living with obesity (31). Specifically, the participants’ reported experiences were indicative of ‘courtesy stigma’ in which a person is stigmatized because of his close association with another person with a stigmatizing feature (29). Since obese children are often victims of social stigmatization (43) and caregivers are regarded by others as directly contributing to or primarily to blame for their child’s obesity, (30) the finding that caregivers of children in KidFit experienced courtesy stigma is not surprising. Coping with courtesy stigma has been shown to add a significant burden to parents of children with chronic diseases or intellectual or physical disabilities (25–28). Courtesy stigma has also been associated with reduced parental quality of life (44) and may impede parent–child interactions and children’s social functioning (45). Therefore, offering programmes that include structured social support for caregivers could help mitigate the negative impact of courtesy stigma (44) and improve outcomes (42). Since, participants spoke positively about the KidFit group-based sessions because of the social support, which has also been reported in a prior study (46), offering more structured support around courtesy stigma in this setting might help caregivers develop skills to manage these feelings after programme completion.

There are several limitations to this project that should be considered. The generalizability of findings is limited by the qualitative design, sample size, and data collected in a single setting. The feedback session guides were primarily developed for quality improvement and programme development purposes to elicit feedback about programme components and logistics, which limited the ability to probe specific comments regarding caregiver experiences of personal responsibility, blame and social judgment. In the

future, we plan to more fully explore these themes. Additionally, a caregiver stakeholder group could be engaged to inform the design of the interview guide and to provide feedback with qualitative findings. Despite these limitations, we believe that our findings are likely not unique to our local setting and are of value to other paediatric weight management programmes.

Implications for practice and future research

Obtaining caregiver feedback during programme development provided valuable insights about the importance of clinic staff in delivering and reinforcing healthy lifestyle messages, caregiver experiences of courtesy stigma, and the value of support to help caregivers manage feelings of courtesy stigma. In the next iteration of the programme, KidFit plans to continue to embed feedback opportunities and also to provide a role playing session for family caregivers to model positively framed messages related to lifestyle changes for youth with obesity. Although the intent was not to specifically explore courtesy stigma experienced by caregivers, caregivers' feelings of personal responsibility, blame and social judgment were consistently communicated during the programme feedback sessions. There are very few studies in the extant literature that specifically explore the courtesy stigma experienced by caregivers of obese children (23–25,41), and to our knowledge, there are no interventions describing how to support caregivers with these experiences. In the future, KidFit plans to include specific sessions related to parental feelings of shame and blame during the group programming. The experiences of courtesy stigma by the caregivers in KidFit are likely not unique. We suggest that other obesity programmes might consider providing healthy lifestyle education in a manner that ameliorates caregivers' tendencies to internalize discourses of social judgement and blame. Future studies could more comprehensively examine the cost-effectiveness of providing caregiver support sessions for courtesy stigma and the impact on treatment outcomes.

Conflict of Interest Statement

No conflict of interest was declared.

Author contributions

ISZ conceptualized and designed the quality improvement project, designed the data collection instruments, was responsible for oversight of data collection, contributed to the analytic design, and drafted the initial manuscript. BT conceptualized the analytic design, and performed the statistical analyses. JG, CU and AW contributed to the design of the quality improvement project, designed the data collection instruments, and coordinated and supervised data

collection. EM conceptualized and designed the quality improvement project, and contributed to the analytic design. All authors critically reviewed the manuscript and approved the final manuscript as submitted.

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