Why do parents discontinue health services for managing paediatric obesity? 
A multi-centre, qualitative study

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KEYWORDS
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Parents; 
Patient dropouts; 
Paediatric obesity; 
Qualitative research

Summary
Objective: To explore parents’ reasons for discontinuing tertiary-level care for paediatric weight management.

Methods: Participants were parents of 10–17 year olds (body mass index [BMI] ≥85th percentile) who were referred for paediatric weight management. Parents were recruited from three Canadian sites (Vancouver, BC; Edmonton, AB; Hamilton, ON) and were eligible if their children attended at least one clinical appointment and subsequently discontinued care. Data were collected using semi-structured individual interviews that were digitally recorded, transcribed, and analysed using an inductive manifest content analysis.

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Results: Parents (n = 29) of children [mean age: 14.7 ± 1.8 years; mean BMI percentile: 98.9 ± 1.6; n = 17 (58.6%) boys] were primarily female (n = 26; 89.7%), Caucasian (n = 22; 75.9%), and had a university degree (n = 23; 79.3%). Reasons for discontinuing care were grouped into three categories: (i) family factors (e.g., perceived lack of progress, lack of family support, children’s lack of motivation), (ii) logistical factors (e.g., monetary costs, distance, scheduling), and (iii) health services factors (e.g., unmet expectations of care, perceived limited menu of services, no perceived need for further support).

Conclusions: A range of multi-level factors influenced attrition from tertiary-level paediatric weight management. Our data suggest that experimental research is needed to examine whether addressing reasons for attrition can enhance families’ retention in care and ultimately improve health outcomes for children living with obesity.

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Introduction

Success in managing childhood obesity is linked to continued engagement in clinical care [1], but many children drop out of treatment prematurely [2]. A recent review showed that up to 83% of children enrolled in lifestyle interventions for weight management dropped out of care [3]. Attrition, defined broadly as discontinuing care prematurely, is a concern given that children who drop out of care are unlikely to receive the full benefits of treatment [4]. Further, attrition results in an inefficient use of resources and can create feelings of failure among both families and clinicians [5,6]. These consequences highlight the need to better understand why families discontinue care, particularly those children who are referred to specialised services for managing obesity since they often present with complex psychosocial and medical health issues [7].

To date, most research on attrition in paediatric weight management has focused on demographic, anthropometric, and psychological factors [5,8,9]. We recently completed a review and reported that ethnicity, socioeconomic status, and higher BMI predicted attrition, but the findings were mixed and inconsistent [3]. These findings offered limited insights into families’ perspectives of weight management services, which might be more proximally linked to their decision to discontinue care. Most studies on parents’ [5,10–12] and clinicians’ [6,13] perspectives regarding attrition have been conducted in the United States [3], so perceived contributors of attrition in contexts with different demographic, social, cultural, and health system characteristics remain to be understood. Furthermore, unlike attrition from obesity-related trials or interventions, families’ perceptions of and experiences in health services for obesity management have not been well-studied, so little is known about whether clinical health services meet the needs and expectations of families or if they contribute to attrition [14]. Qualitative health services research is very well-suited to understand factors that can influence attrition, but to date, this approach has been underutilised in this area of study. Therefore, our purpose was to explore the reasons that led parents to discontinue care for managing paediatric obesity in tertiary level, paediatric weight management clinics in Canada.

Methods

Design

The current report was part of a larger, qualitative study that was designed to understand the factors underlying families’ decisions to initiate, continue, and terminate health services for managing paediatric obesity [15]. This report complements articles we published previously regarding parents’ reasons related to initiating care [16], not initiating care [17], and recommendations for improving health services for obesity management [18]. Prior to commencing recruitment and data collection, ethics approvals for the study were obtained from three Canadian sites (University of British Columbia [Vancouver, BC]; University of Alberta [Edmonton,
Reasons for discontinuing paediatric obesity management

Table 1  Interview guide to explore parents’ reasons for discontinuing paediatric weight management.

- Who referred you to the program?
- Who decided to come to program and why?
- What did you expect about coming to the program?
- How would you describe your experience in the program?
- Who decided to discontinue the program and why?
- Did you or your child experience any challenge that influenced your decision to not continue care?
- Was the program effective?
- How was the relationship with clinic staff?
- Did you talk to family members or friends about the decision to not continue care? What did they say?
- To what extent were your program expectations met?

AB); McMaster University/Hamilton Health Sciences [Hamilton, ON]).

Study sample

We purposively sampled parents as key informants to understand the reasons behind their decisions to discontinue care [19]. To be eligible for this study, participants must have been parents of children (10–17 years of age; BMI ≥85th percentile) [20] who discontinued treatment in one of the following multidisciplinary clinics: Pediatric Centre for Weight and Health [PCWH; Edmonton, AB], Centre for Healthy Weights: Shapedown BC [CHW; Vancouver, BC], and Metabolism, Obesity, and Health Program [MOHP; Hamilton, ON]. Services provided in these clinics are described elsewhere [18]. Parents were not eligible for the study if they (i) did not speak English and (ii) were not involved in the decision to drop out.

Recruitment

Medical records of children who discontinued care from 2010 to 2013 were screened by research assistants (RAs) at all sites to identify candidates who would be eligible for participation. Mailing addresses and contact information were retrieved from patient databases that were maintained by all three study sites, and parents were then contacted by regular mail, telephone, or e-mail. Once inclusion and exclusion criteria were confirmed with families, informed and written consent was obtained from eligible parents. Interviews were held at times and locations (e.g., clinic or university setting) that were convenient for parents. After their interviews, parents learned that they were eligible to receive a $100 (CDN) gift card to a local business as a token of appreciation for their study participation.

Data collection

Trained RAs conducted individual semi-structured interviews with each parent. The interview guide (see Table 1) included open-ended questions and probes to explore child, parent, family, environment, clinic, and health system factors related to attrition. Interviews were digitally recorded and lasted ~40 min each. In addition, for descriptive purposes, RAs used a standardised protocol and case report form to retrieve demographic, anthropometric, and health services data from children’s medical records.

Data analysis

We transcribed interviews verbatim and used inductive manifest content analysis to analyse the data [21]. First, the lead researcher (JD) read the transcripts to gain a sense of the data as a whole. Second, several transcripts were coded line-by-line to develop a preliminary coding scheme of reasons for attrition. Rules of inclusion were created for each defined reason. Third, the inductively-developed coding scheme was discussed within the research team and used to code the entire dataset. Throughout the analysis, labels of reasons were refined and created on an ‘as-needed’ basis. Fourth, reasons were grouped into broader, higher-order categories that were also discussed within the research team. The analysis continued after data saturation to determine the frequency with which parents indicated each reason for attrition. As a final step, direct quotes were chosen under each category for illustrative purposes.

Results

Parents (n=29) of children (mean age ± standard deviation [SD]: 14.7 ± 1.8 years; BMI percentile:
98.9 ± 1.6; male sex: n = 17; 58.6%) were primarily female (n = 26; 89.7%), Caucasian (n = 22; 75.9%), and had a university degree (n = 23; 79.3%). Time from referral to first clinical appointment was, on average, 3.9 ± 3.2 months. Over this period, families attended 8 ± 6 clinical appointments, which included individual, group, and a combination of individual and group visits. Demographic and anthropometric data of parents and children are presented in Table 2 (anthropometric data were not available for one family). Depending on the issue parents were referring to, reasons for attrition were grouped into three categories: (i) family fac-

Table 2 Demographic and anthropometric characteristics of study participants.

<table>
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<th>Edmonton (n = 9)</th>
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<td>Child</td>
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<tr>
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<td>n = 4</td>
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<td>Height (cm)</td>
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</tbody>
</table>

<sup>a</sup> Overweight (BMI ≥ 25 kg/m²); obese (BMI ≥ 30 kg/m²).

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Factors, (ii) logistical factors, and (iii) health services factors.

Family factors

Perceived lack of progress (n = 24)
Some parents were discouraged and decided to interrupt care because their children were not losing weight as they expected. “I’m not seeing the results I expected after going somewhere for a year. We should have progressed a little bit further. The scale doesn’t move. Then I’m just not gonna bother trying” (Parent 15).

Children’s lack of motivation (n = 21)
Many children were reluctant to continue care, and their parents did not want to force them to continue, or they were unsure how to enhance their children’s motivation for care. “We came to one more appointment. It was after that she said, ‘mom, I’m not going back’. She just says, ‘mom, I don’t want to do it’ and that was that. I can’t force her” (Parent 9).

Perceived lack of family support (n = 11)
Care was discontinued due to frustrations with family members who either undermined or failed to support the implementation of recommended lifestyle changes. “My daughter said ‘well, I’m going eat what I want to eat’. And my husband said ‘well, you know we’re not the ones with the problem’. So their support was like, you go, but we’re not going to help out” (Parent 1).

Logistical factors

Scheduling (n = 16)
Parents reported conflicting schedules as the most difficult barrier to their attendance at clinical appointments. Specifically, they found it challenging to plan around work and school commitments during the day. “The only reason we didn’t come and follow through was the time constraint. The program was working and my child was losing weight at one point, but the fact that I had a very hectic schedule at the time and they don’t have weekend clinics or even after hours made it hard to fit it in. It also meant that my child had to miss school, so it was really quite inconvenient. It was just too much” (Parent 6).

Some parents also found it challenging to attend appointments in the evenings due to other commitments. “My husband and I would finish work at 5:00 pm and the program started at 5:30—8:00 pm or something. We work downtown and we live 20 min away. We have to pick up my child and then with- out eating anything, we go to the clinic. It was very tiring and frustrating” (Parent 2).

Distance (n = 13)
Some parents indicated that distance became a barrier to attend clinical appointments. “The main reason was distance. If it was local, you know, it would have been much easier to jump in the car and go over and do it and come back” (Parent 1).

Cost (n = 9)
A number of parents reported that parking was expensive, which prevented them from coming to attend clinic visits. “Five bucks for parking is a jug of milk that will feed the kids for three days… So people that just don’t have that extra five bucks to park… I know some days, I’m like, well, we have to park far and we have to be late ‘cause like we don’t have five or ten bucks in our budget to spend on parking” (Parent 7).

Health services factors

Unmet care expectations (n = 17)
Some parents found that the information provided was too basic, the support was not structured enough, and the care received was not tailored to their families’ needs and preferences. “The program was pretty straightforward. They were just saying everything I already knew. If I really wanted to do that, then I would’ve just done it myself” (Parent 7).

Limited menu of services (n = 15)
Many parents described a preference for services that they reported were unavailable at their local clinic, including psychological counselling. “I didn’t want her just to be on a diet. I wanted to focus on the psychological aspect… but that is how the program was set. We just talked about exercise every time” (Parent 10).

No perceived need for further support (n = 4)
Some families stopped attending appointments because they felt that they had received the support they needed. “I just think that if I still had a daughter who I felt needed it, I would’ve made it a priority to continue through the various supports. But I don’t think we need it. That’s really what it is, the reason we stopped. I thought we got what we needed from the program” (Parent 21).

Discussion

Our study was designed to explore parents’ reasons for deciding to discontinue paediatric weight management from tertiary level weight management clinics. We found that parents’ reasons referred to a variety of family, logistical, and health services issues, suggesting that multiple factors at different levels influenced attrition. These findings highlighted the need for experimental research to evaluate whether addressing factors identified by parents (most of which were modifiable) can reduce attrition in paediatric weight management [22]. Our findings also support the concept that a menu of health services is required to best support families in managing paediatric obesity as a chronic condition [23].

Our results complement previous reports that have documented families’ lack of motivation as a major barrier to continuing weight management care [6,11,12,24,25]. Limited support from other family members, perceived lack of parental control over children’s decision to discontinue care, and perceived lack of progress in losing weight were all influential factors in our study. Families’ expectations regarding weight loss influenced by dramatic weight losses reported in the media or anecdotally shared by families’ relatives and friends may contrast with the true nature of obesity as a chronic disease [25] that once established can take a long period of time to successfully manage or treat, if at all. Helping individuals with obesity to hold more realistic expectations for what they can expect from clinical interventions might help to reduce attrition; however, at least in the adult obesity literature, the evidence is mixed [26]. It remains to be determined whether providing families with information about typical treatment outcomes (e.g., modest weight loss or weight stability) and working to reduce the discrepancy between expected and likely weight loss at the time of presentation (or during treatment) enhance retention in and satisfaction with care.

Experiencing logistical barriers and perceiving them as difficult to overcome was common among participants in our study. Our data confirmed that distance from health services is a barrier to accessing care for many families. Interestingly, some parents who reported distance as a barrier were not necessarily living farther from the referred clinic which suggests that parent interpretation of distance may include additional factors such as travel time and expenses related to transportation. In lieu of in-person contact, alternative forms of communication (e.g., email, telephone, skype, telemedicine) may be more feasible and desirable for families who perceive distance as a barrier [27,28]. Although the efficacy of distance-support interventions for managing paediatric obesity is modest [29], such modes of support might be best viewed as a complement to in-person care that can keep families connected with clinical programs, especially in times when less intensive services are feasible or desirable.

Many parents indicated that scheduling conflicts were barriers to continuing care, which is consistent with previous research [11–13]. Parents found day-time clinical appointments inconvenient because appointments conflicted with existing work, school, and recreational commitments. Evening appointments has been suggested to address this problem [13]; however, our data showed that families have numerous competing commitments and priorities, so evening clinic times may not be suitable for some families either. Offering weekend appointments is an additional option, but may conflict with the constraints under which clinics and clinicians typically operate including hospital management policies and clinicians’ schedule preferences. Relatedly, same-day counselling or ‘drop in’ appointments have been provided successfully in other areas of health care delivery (e.g., mental health counselling), especially when waitlists are long [30]. To our knowledge, this approach has yet to be evaluated in paediatric weight management, but may have help to improve access, enhance satisfaction with care, and reduce attrition.

Our data confirmed that families’ perceptions and preferences regarding weight management services influenced their decision to discontinue care [10]. For example, some parents (i) preferred individual over group sessions, (ii) considered the information provided at the clinic as too basic, and (iii) believed the clinic did not offer services that they regarded as necessary to manage paediatric obesity. These findings suggested that the mismatch between expected and experienced care played a role in parents’ decision to leave treatment prematurely. Thus, to enhance retention, a family-centred approach that takes into consideration families’ expectations, values, and circumstances when establishing treatment services and goals [13] is likely to be more effective than a one-size-fits-all model of care. A menu of therapeutic options is also better suited to meet the diverse and evolving needs of families over time. For instance, tertiary level clinical programs that include different (i) modes of contact (e.g., 1-on-1 counselling + group-based interventions), (ii) delivery options (e.g., in-person + telemedicine;
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parents and children (parents-only), (iii) variable appointment frequencies (e.g., weekly + monthly appointments), and (iv) intervention strategies (e.g., lifestyle counselling + bariatric surgery) are desirable. However, to our knowledge, we are not aware of any reports suggesting that programs offering a broader menu of services are superior in reducing attrition, improving patient/family satisfaction, and most importantly, managing obesity versus programs that offer fewer therapeutic options. Future research is needed to evaluate the feasibility and effectiveness of clinical programs that vary in their comprehensiveness of care.

Our research was not without limitations. First, children’s interview data were not sufficient to gain insight into their perspectives. Second, most interviewed parents were Caucasian and relatively highly educated, which limits the generalizability of our findings. Third, since most families were interviewed in a clinical setting, social desirability bias may have prevented full disclosure of their views about services offered in the clinics; however, it is unlikely that the gift cards received by parents led to desirability bias since parents received their tokens after their interviews were completed. Lastly, some families attended only a few appointments, which may limit the value of their perspectives to help us understand their decision to leave care prematurely. Interestingly, our experience in contacting and recruiting families for this study led some of them to re-connect with clinics and book appointments to re-engage in care. This anecdotal experience highlighted the potential value of contacting families who previously discontinued care to explore their readiness for treatment and to support them in addressing participation barriers. Future research (not to mention health services quality improvement) in this area may prove insightful as a patient-oriented strategy to help families reconnect with services at a future point in time when they may be more ready, willing, and able to participate in their care.

Conclusions

Family, logistical, and health services factors influenced parents’ decisions to discontinue paediatric weight management. Parents of children who discontinued care described multiple demotivating factors, outlined distance as a barrier, had scheduling difficulties, experienced dissatisfaction with availability and perceived suitability of services, had unmet care expectations, and regarded that further care was not necessary. Our data highlighted the need for multi-level strategies to address attrition, which should focus primarily on enhancing motivation for treatment, developing problem-solving skills (e.g., to address scheduling conflicts), and minimising the impact of personal and contextual barriers (e.g., distance and financial costs). Although several strategies hold promise (e.g., distance support, motivational interviewing), the impact of targeted and tailored approaches to reduce attrition from tertiary level, multidisciplinary clinics for managing paediatric obesity remains to be tested empirically.

Conflict of interest

The authors declare they have no competing interests

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Contributor’s statement

Jasmine Dhaliwal developed and refined the data collection tools, coordinated data collection at all sites, acquired data from one site, interpreted the full dataset, co-authored the first draft of the manuscript, and approved the final manuscript as submitted.

Arnaldo J. Perez helped to organise and analyse the data, revised the manuscript, and approved the final manuscript as submitted

Nicholas L. Holt assisted with study design, revised the manuscript, and approved the final manuscript as submitted.

Rebecca Gokiert assisted with study design, revised the manuscript, and approved the final manuscript as submitted.

Jean-Pierre Chanoiné assisted with study design, oversaw data collection at his site, revised the manuscript, and approved the final manuscript as submitted.
Katherine M. Morrison assisted with study design, oversaw data collection at her site, revised the manuscript, and approved the final manuscript as submitted.

Laurent Legault assisted with study design, revised the manuscript, and approved the final manuscript as submitted.

Arya M. Sharma assisted with study design, revised the manuscript, and approved the final manuscript as submitted.

Geoff D.C. Ball conceptualised and designed the study, co-authored the first draft of the manuscript, and approved the final manuscript as submitted.

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