Why don’t families initiate treatment? A qualitative multicentre study investigating parents’ reasons for declining paediatric weight management

Arnaldo Perez MSc1, Nicholas Holt PhD2, Rebecca Gokiert PhD3, Jean-Pierre Chanoine MD PhD4, Laurent Legault MD5, Katherine Morrison MD6, Arya Sharma MD PhD7, Geoff Ball PhD RD8

BACKGROUND: Many families referred to specialized health services for managing paediatric obesity do not initiate treatment; however, reasons for noninitiation are poorly understood.

OBJECTIVE: To understand parents’ reasons for declining tertiary-level health services for paediatric weight management.

METHOD: Interviews were conducted with 18 parents of children (10 to 17 years of age; body mass index ≥85th percentile) who were referred for weight management, but did not initiate treatment at one of three Canadian multidisciplinary weight management clinics. A semi-structured interview guide was used to elicit parents’ responses about reasons for noninitiation. Interviews were audio-recorded and transcribed verbatim. Data were managed using NVivo 9 (QSR International, Australia) and analyzed thematically.

RESULTS: Most parents (mean age 44.1 years; range 34 to 55 years) were female (n=16 [89%]), obese (n=12 [66%]) and had a university degree (n=13 [71%]). Parents’ reasons for not initiating health services were grouped into five themes: no perceived need for paediatric weight management (eg, perceived children did not have a weight or health problem); no perceived need for further actions (eg, perceived children already had a healthy lifestyle); no intention to initiate recommended care (eg, perceived clinical program was not efficacious); participation barriers (eg, children’s lack of motivation); and situational factors (eg, weather).

CONCLUSION: Physicians should not only discuss the need for and value of specialized care for managing paediatric obesity, but also explore parents’ intention to initiate treatment and address reasons for noninitiation that are within their control.

Key Words: Canada; Obesity; Paediatric; Parent; Qualitative; Treatment

Family-based interventions that emphasize healthy nutrition and physical activity habits combined with behavioural change techniques are efficacious for managing paediatric obesity (1). Families who initiate obesity management can benefit in several ways, including becoming aware of underlying medical issues, being better informed about available care, gaining knowledge about healthy lifestyles and enhancing their initial motivation for treatment. Despite these benefits, a minority of families referred for care choose to initiate paediatric weight management (2,3). Delay in treatment may lead to further unhealthy weight gain and missed opportunities to improve children’s health and well-being. These issues are of concern given that younger children and children with a lower level of obesity are more likely to be successful in obesity management (4).

Both active (eg, physician referral) and passive (eg, newspaper advertisement) methods have been used to recruit children for weight management interventions, but neither tends to yield substantial numbers (5,6). Several anthropometric, sociodemographic and subjective factors have been associated with noninitiation of paediatric weight management. For example, compared with their

©2015 Pulsus Group Inc. All rights reserved
peers, children who are younger, male, less overweight and from low-income families are less likely to initiate care (3,7). Parents’ positive appraisals of their children’s physical well-being and lifestyle habits have also been associated with noninitiation (7).

To date, few studies have examined reasons for noninitiation; of those that have, reasons identified by families include time constraints, distance, participation in other programs and perceived healthy lifestyle of the child (7,8). These reasons have been identified in the context of clinical trials and community-based programs. Given that characteristics of treatment affect initiation (9), reasons for participating in research or community initiatives may differ from reasons for participating in weight management services, which are typically accessed via physician referral. Furthermore, reasons for noninitiation have often been grouped into categories that provide little insight into their underlying meanings.

Understanding families’ decisions to decline multidisciplinary care can help to develop effective strategies that enhance treatment initiation, especially among children whose need for weight management has been determined clinically. The aim of the present multicentre study was to understand parents’ reasons for declining care at multidisciplinary paediatric obesity management clinics.

METHODS

Study design

The present study was part of a larger project designed to understand initiation, continuation and termination of paediatric weight management among families referred for multidisciplinary health services (10). Parents were sampled because they play a primary decision-making role. The study was approved by the Research Ethics Boards at all three study sites (University of British Columbia, Vancouver, British Columbia; University of Alberta, Edmonton, Alberta; and Hamilton Health Sciences/McMaster University, Hamilton, Ontario).

Participants

Between 2011 and 2013, parents were recruited from three Canadian multidisciplinary weight management clinics (in Vancouver, Edmonton and Hamilton) to which their children were referred. Children had to be referred by a physician to receive treatment, which was free of charge. Parents and children were invited to an orientation session (before ever attending the clinic) in which families learned about details of available health services. Although services across participating clinics varied somewhat according to type, length, mode of delivery and content, they shared a similar focus on family-centred care and combined behavioural and cognitive techniques offered by a multidisciplinary team of clinicians (eg, physicians, nurses, dietitians, exercise specialists, psychologists) to enhance lifestyle habits and improve psychosocial and physical outcomes. Parents were eligible to participate in the study if they: had a child (10 to 17 years of age; body mass index [BMI] ≥85th percentile) (11) who was referred to one of the clinics; were present when the referral was made; and declined the referral by not attending any clinical appointment. Parents were ineligible if they did not speak English or French, or if the child had a serious health condition that precluded their participation in the recommended clinic. Contact information for potential participants was obtained via referral forms. On interview completion, participating families received a $100 gift card as a token of appreciation.

Data collection

Written informed consent was obtained from parents before data collection. Semistructured, one-on-one interviews lasting approximately 60 min were conducted by trained research assistants. Open-ended and follow-up questions were asked to explore reasons for the referral, referral context, information received about the clinic, interaction with the referring physician, reasons for declining care, children’s view of the referral and, if applicable, experience in pre-clinical orientation sessions. The interview guide (Table 1) was developed, piloted and reviewed by researchers with expertise in qualitative methods, paediatric obesity and health behaviour. Interviews were digitally recorded and transcribed verbatim. Demographic (eg, age, sex) and measured anthropometric (eg, weight, BMI) data of children were obtained from referral forms.

Data analysis

Transcribed data were entered into NVivo 9 (QSR International, Australia) for data management. Data were analyzed thematically (12). Transcripts were read and re-read for familiarization with the data. A preliminary coding scheme of reasons for noninitiation was developed and discussed with the research team. Data were then coded systematically using the developed coding scheme; when necessary, new codes were added. Related codes were grouped into potential themes. The appropriateness of these groupings was checked in relation to data coded under each theme and the entire dataset. An adequate level of data saturation was achieved at the theme level as each theme provided sufficient details and variety (13). As a final step, quotes that best represented identified reasons for noninitiation were chosen to illustrate the study results. Several techniques were used to ensure rigour of the analysis including triangulation of data from different settings, peer checking and comparison of alternative forms of interpretation of the data (14).

RESULTS

Eighteen parents (mean age 44.1 years; range 34 to 55 years) were interviewed approximately one year (11.1±7.0 months) after children were referred for care in Vancouver (n=5), Edmonton (n=3), and Hamilton (n=10). Most participants were female (n=16 [89%]), Caucasian (n=15 [83%]), had objectively measured obesity (BMI ≥30.0 kg/m2; n=12 [66%]), held a university degree (n=13 [71%]) and had an annual household income >$50,000 (n=10 [56%]). All children of interviewed parents met the criteria for obesity (BMI ≥95th percentile; mean BMI percentile 98.9). On average, children were 13.9 years of age (range 10 to 17 years) and most (n=10 [56%]) were girls. Parents provided several reasons for not initiating paediatric weight management, which were grouped into five themes: no perceived need for weight management; no perceived need for further actions; no intention to initiate recommended care; participation barriers; and situational factors. The themes, subthemes (reasons) and corresponding quotes are presented in Table 2.

### TABLE 1

<table>
<thead>
<tr>
<th>Interview guide for parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Why was your child referred to the program?</td>
</tr>
<tr>
<td>• What did the physician tell you about the program?</td>
</tr>
<tr>
<td>• What did you and your child think about coming to the program?</td>
</tr>
<tr>
<td>• To what extent did your child need the recommended program?</td>
</tr>
<tr>
<td>• Who was involved in the decision to not come to the program?</td>
</tr>
<tr>
<td>• What were the reasons for not coming to the program?</td>
</tr>
<tr>
<td>• What were your thoughts and feelings after the orientation session?</td>
</tr>
<tr>
<td>• How confident were you in meeting the requirements of the program including attendance?</td>
</tr>
</tbody>
</table>

The present study was...
No perceived need for weight management
All parents had children who satisfied the clinical definition of obesity; however, several did not perceive the need for weight management. Some (n=4) did not believe their child had a weight problem that needed to be addressed due to a recent weight loss, the belief that the child will outgrow obesity, the perceived low degree of overweight and the attribution of weight gain to muscle. Two parents were aware of their children’s overweight status, but were not concerned because they believed their children were physically healthy.

No perceived need for further actions
Some parents perceived the need for weight management, but did not believe further actions were needed by the time they were contacted by the clinic. This perception was based on the assumption that their children’s current behaviour was adequate to manage obesity. Parents who believed that additional actions were not necessary reported that their children were already receiving appropriate support for weight management (n=4) or already had a healthy lifestyle (n=2).

No intention to undertake the recommended care
Parents who perceived the need for taking further action did not necessarily intend to enroll their child in the recommended clinic. In fact, most of the reasons parents provided showed that they had not formed the intention to initiate the recommended care. Some parents (n=11) were hesitant to participate because of the psychological (ie, reinforcing the weight problem), educational (ie, children taking time away from school) and financial costs (eg, transportation, parents taking time off from work) associated with initiation. Perceived low effectiveness of the weight management program also undermined parents’ intention to initiate treatment (n=5). Those who regarded the referred program as ineffective stated that: a focus on lifestyle habits would not address the root cause (eg, metabolic problems) of the children’s unhealthy weight; it would rely too heavily on families to manage children’s obesity rather than address the issue with children directly; care would be delivered primarily through group-based sessions whereas one-on-one sessions were preferred; it would focus too much on children rather than on the family as a whole; and care would be provided by specialists who appeared to ignore the complexity of obesity by offering limited advice (eg, eat less, exercise more). Furthermore, the intention to initiate treatment was weakened by the perceived lack of control (n=5) over expected program demands including helping children to make lifestyle changes and limiting their access to unhealthy foods in different settings (eg, school, community) as well as families’ preference (n=4) for an alternative option (eg, self-management).

Initiation barriers
Some parents appeared to have formed the intention to initiate the recommended care, but did not engage in treatment due to external

TABLE 2
Parental perspectives of reasons for declining paediatric weight management

<table>
<thead>
<tr>
<th>Themes</th>
<th>Reasons</th>
<th>Selected quotes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>No perceived need for care</td>
<td>No perceived weight problem</td>
<td>“Another reason was that when we finally did get the referral, she [the child] had lost a fair amount of weight already.”</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>No perceived health problem</td>
<td>“We don’t see it [child’s weight] now as a health scare. If there is something else you know health wise and you can see it instantly, we would jump in to say OK, we gotta do something, right?”</td>
<td>2</td>
</tr>
<tr>
<td>No perceived need for further actions</td>
<td>Current involvement in weight management</td>
<td>“My daughter is currently in a program in which she’s lost 25 pounds already.”</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Perceived healthy lifestyle</td>
<td>“The doctor knows she [the child] is active. She is not like some kids who are eating all day. She is out doing things, so I don’t think there’s anything else she could have done.”</td>
<td>2</td>
</tr>
<tr>
<td>No intention to initiate the recommended care</td>
<td>Associated costs</td>
<td>“If one person’s struggling, you don’t really want to sort of highlight that. She [the child] is very private. And there is still the stigma you don’t want to be one of the fat girls, you know what I mean. Well, I mean it’s horrible to say that’s her.”</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Perceived lack of effectiveness</td>
<td>“The program was less calories, more exercise and that had already been well-tried and was providing absolutely no results.”</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Perceived lack of control</td>
<td>“He doesn’t exercise enough and eats too much of the bad things. When he comes from the school, I am not there to watch him. I can’t do anything.”</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Preference for an alternative source of management</td>
<td>“In her case, she [the child] took the problem [excess weight] under her own control and she dealt with it.”</td>
<td>4</td>
</tr>
<tr>
<td>Initiation barriers</td>
<td>Lack of time or conflicting schedule</td>
<td>“Another issue is to find a night where I’ve got a couple of hours to get down here. Time is definitely one of the major issues. And my husband works many evenings.”</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Children’s lack of motivation</td>
<td>“She doesn’t say too much, she just says I don’t want to participate, I don’t want to, I don’t want to.”</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Parents’ accounts for not addressing children’s lack of motivation</td>
<td>“I don’t know how you make somebody ready. You can’t make them [children] ready. You can give them tools and information when they are ready.” (motivational belief)</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Distance or transportation problems</td>
<td>“I would definitely be, you know, enrolling her in that program. Um, it was just the distance that I wasn’t able to travel every week for.”</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Misperception</td>
<td>“I thought it was gonna be more like every other Wednesday evening which was kind of my hesitancy to commit to doing something like that right. So it wouldn’t be an issue at all if it’s in the daytime or once a month. I can make that work. So that’s good to know.”</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Personality trait</td>
<td>“So that’s why I never really ever did rebook that appointment because it’s laziness, I know it.”</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Personal illness</td>
<td>“I’ve been dealing with an illness myself that has also not helped them [children] on being motivated. Now, I’m getting better and I wanna, you know, start exploring different options.”</td>
<td>1</td>
</tr>
<tr>
<td>Situational factors</td>
<td>Weather, tiredness, forgetfulness</td>
<td>“But I remember that day in March. The weather was bad and we could not make it.”</td>
<td>3</td>
</tr>
</tbody>
</table>
and internal barriers. External barriers included lack of time/conflicting schedule (n=11), child’s lack of motivation (n=7), distance from home or transportation problems (n=5). Parents did not refer to specific strategies to address participation barriers. Instead, they highlighted some difficulties to overcoming them. For example, parents’ accounts for not addressing their children’s lack of motivation included: lack of knowledge and confidence regarding how to encourage children to participate; belief that motivation must come from within; intention to avoid an additional source of stress in their children’s lives; and belief that pushing children to participate may undermine their willingness to initiate treatment in the future. Internal barriers included misperceptions of the referred care (n=3), self-identified personal characteristics (eg, procrastination) (n=2) and personal illnesses (n=1). Misperceptions arose during interviews when parents realized that some of their perceptions that deterred them from engaging in care (eg, program length, appointment frequency and hours of operation) were inaccurate.

**Situational factors**

Some parents (n=3) indicated factors that appeared to be situational in nature when accounting for missing their initial clinical appointment. Among these factors were forgetting or missing booked appointments (n=1), being tired after work (n=1) and adverse weather conditions (n=1).

**DISCUSSION**

In examining the reasons that led parents to decline paediatric weight management, we identified several themes, including: no perceived need for weight management; no perceived need for further actions; no intention to initiate the recommended care; initiation barriers; and situational factors. These themes can also be regarded as necessary conditions for parents to initiate treatment given their similarities with key constructs (eg, perceived risk, behavioural motivation and barriers) of prominent health behaviour theories, including the Health Belief Model (15), Social Cognitive Theories (16) and Major Theorists’ Model of Behavior (17), used to explain behavioural intention and actual behaviour. It appears to be unlikely that parents will engage in paediatric weight management if they do not perceive the need for care, believe that further actions are unnecessary, have no intention to initiate the recommended care or face major/unexpected barriers to initiating treatment.

In terms of treatment motivation, the difference between parents’ perceived need for weight management and their intention to engage in the recommended care is consistent with that of goal intention and behaviour intention. According to Gollwitzer (18), the former refers to the intention to pursue a goal while the latter refers to the intention to perform a particular behaviour to achieve that goal. Thus, individuals may not have even formed the intention to accomplish a goal (eg, manage children’s weight status) or they may have this intention, but not the intention to perform the recommended behaviour to achieve the goal (eg, engage in tertiary level weight management). The assumption that parents did not engage in paediatric weight management because they were not interested in the recommended treatment should be interpreted with caution. More fundamental reasons related to goal intention and intentions to perform further actions and overcome existing barriers may also explain parents’ refusal of care.

Referring physicians may be able to enhance initiation by tailoring their interventions to each family’s situation and level of readiness for initiation. For example, providing families with more information about the clinic may be of little benefit if parents believe that their child does not have a weight problem, or that their current lifestyle behaviours are adequate to address obesity. Similarly, encouraging families to engage in the recommended care by discussing children’s weight status and the health-related consequences of obesity may not be sufficient to enhance treatment initiation among those who prefer self-management strategies or face major barriers to treatment initiation. These interventions may need to vary depending on whether families have formed the intentions or are impeded to act upon formed intentions (19). Several clinical tools and techniques (20-24) are available and can assist clinicians to help families form and act on health care intentions.

Empirically, our results are consistent with findings of previous studies that identified practical, motivational and perceptual factors related to nonparticipation (7,8,25). However, we identified several novel reasons that led parents to decline care, including costs associated with participation, perceived low control over expected program demands, perceived low effectiveness of the intervention and internal barriers (eg, program misperceptions), all of which broaden our view of issues that preclude treatment initiation. Identified reasons for noninitiation suggest that informing families about the need for weight management and recommending a paediatric weight management program are insufficient to ensure treatment initiation. Parents of children with obesity are known to distrust physicians’ assessments, may not perceive excess weight as a health condition that needs immediate attention and tend to underestimate their children’s weight status (26-28). Particularly, the perceived need for weight management appears to be influenced by perceptions such as perceived versus actual weight status, weight gain attributions, perceived susceptibility to obesity and perceived severity of obesity. Consequently, along with determining whether the unwillingness to initiate care is driven by the lack of perceived need for weight management, it is important to know which underlying perceptions lead families to misperceive this need.

Our data also suggest that the decision to decline treatment is made in the context of other behavioural options and pressing needs. Families’ competing commitments appeared to affect initiation by constraining their time to engage in care. Whether treatment was initiated appeared to depend on the extent to which competing behaviours were regarded as easier and more desirable (29) and other issues were regarded as more important. Thus, a more thorough explanation of treatment initiation needs to consider alternative behaviours and other issues demanding equal or greater attention and resources from families.

It is noteworthy that the parents in our study did not take action to address initiation barriers due to a perceived lack of knowledge and skills, as well as the costs associated with taking action. This suggests that the presence of barriers were not what ultimately led parents to decline care, but their perceived inability to overcome them. On the other hand, parents can also overestimate their control over barriers, which may prevent them from implementing planned actions, especially in circumstances in which perceived control over barriers exceeded actual control (30).

Parents were also very sensitive to barriers and program shortcomings, which may have been influenced by their lack of motivation to enroll in the recommended care. Less motivated parents are more likely to perceive more barriers than motivated parents (31). Thus, reported barriers may have indicated real impediments to participate or a coping mechanism (eg, rationalization, denial) to avoid uncomfortable thoughts and feelings for not taking action. The extent to which parents’ reported barriers or other types of reasons for declining care reflect real struggles, coping mechanisms or a combination of both remains to be explored.

We also identified situational factors that appeared to affect families’ attendance, but not the decision to initiate treatment. In
Parents reported multiple reasons for declining paediatric weight management. Some parents did not initiate care because they did not perceive the need for weight management or further actions, while others were not interested in the recommended care or faced participation barriers. Interventions to enhance treatment initiation need to be tailored to families' (and particularly parents') level of readiness to engage in paediatric weight management. Greater emphasis needs to be placed on helping families to incorporate paediatric weight management into their schedules, addressing some of the costs attributed to initiating and motivating children to participate in treatment. Complementary research is needed to understand the reasons for families to initiate paediatric weight management.

CONCLUSION

Parents’ reasons for declining paediatric weight management

Parents who referred to these factors provided reasons that were nested within other categories when a new appointment was scheduled. It is worth noting, however, that unexpected, transient circumstances (eg, family emergencies) may hinder the translation of intentions into behaviour (32). Figure 1 presents a preliminary framework developed to account for parents’ decision to initiate paediatric weight management based on study findings.

Our study had some limitations that need to be acknowledged, including: a small sample size that reduces generalization of study results; reliance on retrospective recall; use of parents’ stated reasons as proxies for actual determinants of the decision to decline care; and absence of children’s perspectives regarding not initiating care. As part of our larger study (10), additional analyses are underway to explore families’ reasons and decisions regarding initiating care following a referral, continuing care for an extended period and discontinuing care prematurely, all of which will enable us to optimize health services for managing paediatric obesity.

ACKNOWLEDGMENTS: The authors thank all of the families who participated in this study. As well, Lisa Watt, Vivian Vaughn Williams, Evert Huie, Jasmine Dhaliwal and Biagiana-Carla Farnesi are acknowledged for their assistance in collecting and managing study data across our study sites. During this research, AP was supported by a graduate studentship from the Women & Children’s Health Research Institute (University of Alberta, Edmonton, Alberta). This study was funded by an operating grant (MOP-106648) awarded to GB from the Canadian Institutes of Health Research.

REFERENCES